Action for Sick Children Scotland

Parental Access and Family Facilities Survey

2012/13

Helping sick children and young people meet their healthcare needs

Prepared by Axiom Consultancy (Scotland) Ltd on behalf of Action for Sick Children Scotland

Survey supported by the Scottish Government Health and Social Care Directorate

axiom
Market Research & Consultancy

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Final thanks go to the ASCS team involved and, in particular, to the Project Steering Group: Richard Olver (Chair), Liz May, Gwen Garner and Zoe Dunhill.

Foreword

This is the seventh survey of Scottish hospitals admitting children and young people but the first to be carried out electronically. It is certainly the most comprehensive to date. Since the first survey in 1985 there have been very significant improvements in both parental access and family facilities. As in 2005/7, the 2012/13 survey has been funded by the Scottish Government with whom Action for Sick Children Scotland (ASCS) has a long record of working in partnership to improve the care of sick children and young people in hospital and in the community.

The Charter of the European Association for Children in Hospital (EACH), which is itself underpinned by the United Nations Convention on the Rights of the Child, sets the key standards for the care of children in hospital and it is for this reason we have benchmarked the survey findings against the ten articles of the Charter. While the survey has found many examples of good practice, the picture is uneven both within boards and across the system.

Where shortcomings have been revealed by the survey, for example the continuing practice of admitting children to adult wards or failure to make educational provision for all admitted children, it is not for want of appropriate Scottish Government guidance. ASCS wholeheartedly supports the government's strategies and policies for children and young people set out in Getting It Right for Every Child and the new Children and Young People (Scotland) Bill, and the principle of patient-centred care. Furthermore, the Scottish Government has committed to the ten articles of the EACH Charter.

While there have, for example, been marked improvements in open visiting and overnight accommodation for parents and carers, certain ward procedures and facilities for children remain suboptimal. Where the apparent failure to meet the standards of the relevant EACH Charter article is attributable to physical constraints, such as lack of space, we have flagged this up. However, many of the failures appear to be due to a failure to implement Scottish Government policy, such as having a dedicated named nurse or giving young people a say in the type of ward to which they are admitted. The problem is compounded by an apparent failure to monitor implementation and a lack of accountability.

The survey commissioned by ASCS has been carried out by an independent research team, well versed in the workings of the NHS, and its findings should be regarded as objective. However, their significance is open to different interpretations. For example, should we regard it as highly satisfactory that two thirds of wards report that parents can stay with their child until anaesthetised and be present in the recovery room after surgery or is it quite unacceptable that a third of wards report that children are denied this parental support in what is a frightening environment?

It could be argued that the relevance of the survey is somehow diminished by the fact that since the last survey the structure of health services for children has changed, as have the respondents. This, however, is precisely the reason for repetitive surveys asking broadly the same questions at the same level within the system to see how changes in the organisation of the service have impacted on parental access and family facilities, following the methodology of, for example, the Scottish Household Survey.

The limited response to the separate survey sent to Child Health Commissioners, whose role we have wholeheartedly supported since their introduction in 2000, was unexpected and has caused us to speculate as to whether CHCs are given the time and resources by their health boards to carry out their responsibilities properly. Anecdotal evidence suggests that, for some, the role of Child Health Commissioner is a very small part of their overall responsibilities. The new children's facilities in Scotland, including the planned children's hospitals for Glasgow and Edinburgh, have the potential to take the hospital care of children to a new level, but only if the Child Health Commissioners are given the tools to do their job.

Scotland's one million plus children (under 18 years) account for a fifth of the population but a third of the nation's life expectancy and 100% of its future workforce. There is thus an economic necessity, as well as a moral imperative, to get it right for every child and I believe that Action for Sick Children Scotland and the Scottish Government, working in partnership, can bring this goal closer to reality.

Richard Olver
Chair, Action for Sick Children Scotland

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The following Appendices to the Survey Report can be emailed on request from ASCS or can be viewed/downloaded from ASCS's website on www.ascscotland.org.uk/default.asp?page=19

Appendix 1: EACH Charter articles

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Executive Summary

1 Background

Action for Sick Children Scotland (ASCS) is a registered Scottish charity which aims to improve standards in healthcare provision for children and young people. A key aspect of its work is promoting high quality healthcare services for children and young people, including equality of services and service access across Scotland.

Since 1985 ASCS has carried out periodic surveys of Scottish NHS hospitals admitting children. ASCS commissioned its seventh survey in 2012, funded by the Scottish Government, to assess current parental access and family provision, to highlight progress and where improvements need to be made. Survey results were cross referenced against the ten articles of the European Association for Children in Hospital (EACH) Charter key standards for paediatric care. (See page 10).

2 Research method

The 66 respondents worked in general hospitals (30), children's hospitals (28) and community hospitals (8) and represented all 14 health board areas. The wards surveyed comprised 30 children's wards, 14 neonatal or paediatric intensive care or special care baby units and 22 other wards. Visits were also conducted to six hospitals to explore parents' experiences of visiting and staying with their child in hospital and staff experiences of providing care. (See page 14 for list of participating hospitals).

Child Health Commissioners were asked to provide an overview of children and young people's health services in their area as well as information on child admissions and staff.

Definitions: For the purposes of this survey, 'parent' refers to a parent or carer, a carer being someone who has long term responsibility for a child and may, or may not, be the parent, and a parent substitute is a temporary replacement for a parent (e.g. a relative or family friend).

3 Conclusions

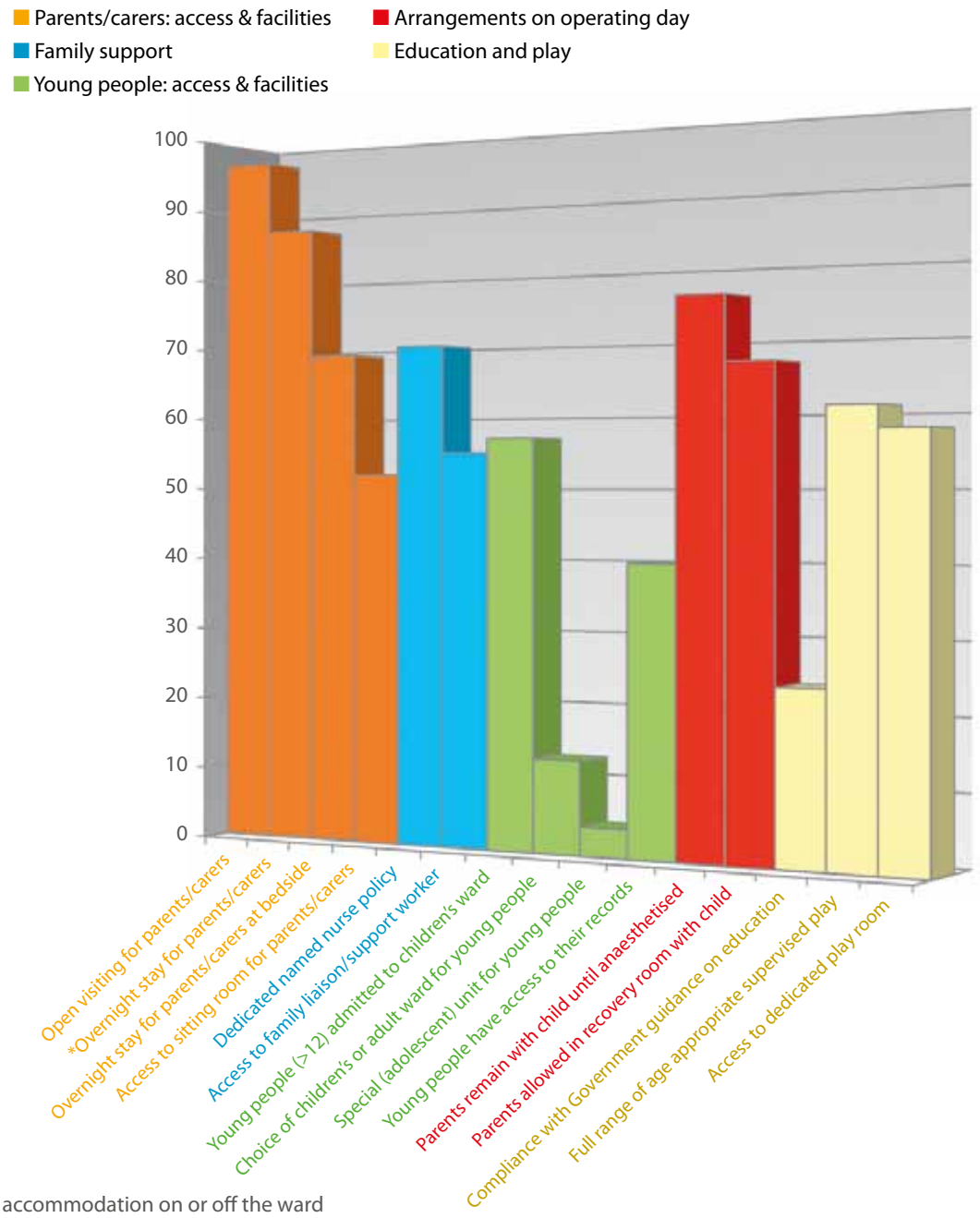
3.1 Parental access

Wards appear to be flexible in their approach to visiting and offer virtually unrestricted access to parents whose children have been admitted, with the exception of restricted visiting in adult wards. However, access appears to be more restricted for parent substitutes with 31% of wards restricting visiting, with some allowing visiting only by agreement or at limited times. Visiting is also more restricted for siblings and few wards appear to have access to crèche facilities.

3.2 Parental facilities and accommodation

A third of wards admitting children do not offer overnight accommodation to parents or parent substitutes at the child's bedside. While the survey suggests that improvements have been made in the availability of off-ward parental accommodation, more than one in ten (13%) of parent/carers cannot stay overnight on site, on or off the ward. Restrictions in space on some wards limits opportunities for parents or siblings to stay or restricts the option of overnight stays to one parent only.

Key Findings: Ward Facilities and Access (%)



* in accommodation on or off the ward

Adult wards generally do not have sitting rooms for parents. Indeed many have no facilities for parents at all. This is a concern given that, in some health board areas, young people from the age of 12 are admitted to adult wards (despite Scottish Government guidance that children up to the age of 16 should be admitted to paediatric facilities). Lack of parental facilities means that parents are not offered the opportunity to take a break during their visit or to stay overnight with their child.

Family support appears to be focused on social work as opposed to other support services. Also, nearly half of neonatal wards or special care baby units did not operate a named nurse policy. Feedback during discussions with parents suggests that they are often unaware of the support available to them and/or of their financial entitlements.

Lack of laundry and kitchen facilities was an issue identified from the survey and raised by parents during the hospital visits. This means that parents incur additional costs when visiting their child in hospital (contrary to article 3 in the EACH Charter). Parents' access to refreshments and meals is variable with few self-catering facilities available. Whilst the survey suggests that parents/carers can access drinks free of charge, the majority of wards are unable to provide free or even subsidised meals.

Feedback from staff and parents during the hospital visits suggests that wards are not able to allow parents to eat on the wards. Parents expressed concern at having to leave their child to go to the hospital canteen as, in many hospitals, it is some considerable distance from the ward. As a result, some parents rely on vending machines, food brought in by relatives or even skip meals.

3.3 Children's mealtimes

Less than two thirds of wards (62%) have specific menus for children/young people and even fewer (55%) supply age appropriate cutlery and tableware. Less than half (42%) supply information about the nutritional value of their meals. One in five wards does none of this. These wards tend to be adult wards in general hospitals but one is a children's ward. Only one ward was able to indicate the daily spend per child on children's meals (£1.67).

3.4 Young people's services

A significant number (43%) of wards surveyed do not accommodate children aged 12 and above on the children's wards. Of these, 2% of wards accommodate children over 12 years in a special unit. Of the 57% which do accommodate children over 12 years, half accept children up to the age of 14 and half up to the age of 16.

Wards appear to recognise the importance of engaging with young people and do involve them in discussions about their treatment etc., but there has been a substantial reduction in the number of wards giving young people the choice of admission to a child or adult ward. Many of the children's ward facilities are more appropriate for children than for young people and few have adolescent specific areas either for beds or for recreation. The recreation equipment is also limited for young people (contrary to articles 6 and 7 of the EACH charter).

3.5 Ambulatory care, short stay and surgery

Whilst there have been improvements in parental opportunities to stay with their child prior to surgery, there has been a reduction in opportunities to be with their child whilst they are anaesthetised and opportunities to be with their child in the recovery room remain low. Practice varies depending on ward type with adult wards, neonatal wards and special care baby units being least likely to allow parents to accompany children to surgery – indeed one in five of all wards did not allow this at all (contrary to article 4 of the EACH Charter).

3.6 Records and feedback

The survey suggests that wards are engaging with parents/carers, children and young people to obtain their feedback on service provision and design. However, few wards appear to facilitate parents/carers or young people's access to their records. The wards have procedures in place for parents/carers or young people to request access but these are often lengthy and therefore only appropriate for patients with longer lengths of stay. Feedback from parents during the hospital visits suggests that they are not aware that they can access the records.

3.7 Travel

The survey indicates an increase in the number of wards making an effort to provide information available to parents on travel costs. However, feedback from parents during the hospital visits suggests that they are not aware of their entitlement to travel cost reimbursement. Often this information is available in admission documentation and it may be that parents of children admitted in an emergency do not receive this information.

3.8 Education

None of the adult wards surveyed indicated that they provide access to teaching for children and young people. Where a reason was given, it was that admissions were too short to warrant such provision. However, brevity of stay seems unlikely to be relevant in all cases as admissions to orthopaedic wards, for example, are often protracted.

Delays in requesting education after admission appear to have been reduced with the majority of wards requesting this after children have been in hospital for one week as opposed to two weeks previously reported. However, according to Scottish Government Guidance on Education of Children Absent from School through Ill-Health (2001), education should be provided after 5 days (assuming the child's health makes it appropriate) or immediately where it is known that a child is likely to be in hospital more than 5 days. Compliance with the Guidance in children's wards has improved but remains low at 24%.

Whilst education is provided in all children's wards, it is impossible to gauge its adequacy since wards were unable to provide details on how much time is spent in education per day per child. Furthermore, the survey suggests a limited availability of both dedicated classrooms and additional support teachers.

Just over a quarter of wards reported that they do not provide education for children from other local authority areas. This may reflect differing arrangements between health boards and local authorities for funding of teaching support. Few wards have access to a teacher from the child's local school.

3.9 Play

There appears to have been an increase in play staff since the previous survey. However, play staff interviewed in the ward visits highlighted difficulties in obtaining training for play specialists. The course is no longer offered in Scotland and is not available through e-learning, making it very difficult for play staff in Scottish hospitals to improve their skills and knowledge and seek promotion. Play staff are concerned that this may limit the number of trained staff in hospitals in the future.

Parents and their children are not allowed to use play areas unsupervised in more than a third (36%) of wards. This, combined with a lack of access to play facilities at the weekends in 26% of wards, restricts availability for play for some children.

Recreation facilities for young people are very limited. The survey highlights the limited availability of adolescent specific facilities and feedback from the hospital visits also highlights limitations in recreational opportunities for young people. Access to the internet is also limited, available in less than half of the wards. Many of the games etc. available on the wards are more suitable for younger children.

The survey also suggests that improvements may be needed in the provision of play preparation, distraction therapy and post procedural play, since the results indicate that not all babies, children and young people receive this consistently.

3.10 Child Health Commissioners

Only 7 out of 14 Child Health Commissioners (CHCs) responded to the survey specifically addressed to them. Data from the CHCs was limited as respondents did not appear to have the required information readily available, and the information they held relating to admissions of young people was particularly limited. This is in spite of the fact that a key responsibility laid upon CHCs is to ensure that appropriate information systems are in place to ensure the provision and monitoring of child health services (National Template for Child Health Services, 2000).

The role of the CHC appears to lack clarity and consistency with health boards adopting different approaches to the role and the priority given to it.

4 Progress since the previous survey

There have been some changes to a few questions and some new questions included since the last survey in 2005/07. However, where the questions asked in this survey are the same as those in the last, comparisons have been made to highlight areas where improvements have been made, areas which have remained the same and areas where there has been some reduction in service provision.

In general, we are confident that the changes shown in the traffic light display represent actual changes in levels of provision. Nevertheless, it is possible that, on occasion, the consolidation of a clinical service onto fewer sites might have a paradoxical effect, apparently reducing facilities but resulting in a more effective service.

The results are presented as a "traffic light" display where there has been:

- Progress since the previous survey
- No change since the previous survey
- A reduction in provision since the previous survey

The colour of a traffic light should not be taken as indicating the adequacy, or otherwise, of provision of access or a facility but only the change.

Issue			Result
Parental access	2005/7	2012/13	
Provision of open visiting for parent/carers	100%	97%	
Provision of facilities and accommodation			
Availability of parents' overnight accommodation at bedside	70%	69%	
Cafe facilities accessible to parents/carers	92%	83%	
The provision of vending machines	74%	87%	
Self-catering facilities for parents/carers	38%	13%	
Family support			
Availability of family liaison/support workers	38%	55%	
Use of a dedicated named nurse policy	84%	70%	
Young people's services			
Choice of child or adult wards for young people	29%	13%	
Ambulatory care, short stay and surgery			
Dedicated day surgery ward	59%	44%	
Dedicated day surgery lists	59%	62%	
Allowing parents to remain with their child till anaesthetised	89%	76%	
Allowing parents to remain in the recovery room	69%	67%	
Records and feedback			
Information for parents on reimbursement of travel costs	83%	88%	
Education and play			
Availability of play specialists	55%	70%	
Availability of dedicated play room (excluded neonatal wards)	59%	58%	
Compliance with Scottish Govt. guidance on education	3%	24%	

5 Recommendations

The recommendations highlight issues which should be addressed to ensure further improvement in the provision of services for children and young people in accordance with the EACH Charter. (See page 10).

5.1 Admissions

- Children and young people under the age of 16 should not be admitted to adult wards and those between 16 and 18 should be given the choice of ward type to which they are admitted.
- The Information Services Division should make information on the admission rates of 15-18 year olds available on its website.
- Adult wards should record the number of children and young people under 18 admitted.
- Consideration should be given to the needs of 16-18 year olds admitted to children's or adult wards.
- Adolescents should be cared for with others of a similar age.

5.2 Information

- Ward staff should ensure that the following information is understood by patients and carers (not just made available), both for elective and emergency admissions:
  - Arrangements for overnight accommodation for parent/carers
  - Availability of family support, including help with travel expenses
  - The named nurse
  - Accommodation, facilities and access for carers.
- There should be:
  - Healthy menus designed specifically for children and young people
  - Information regarding the nutritional value of meals, possibly using a 'traffic lights' system to guide healthy choices
  - Age appropriate cutlery and tableware.

5.3 Parental facilities and accommodation

- All wards admitting children and young people should offer to parent/carers and parent substitutes the following:
  - Overnight accommodation and unrestricted visiting
  - A sitting room close to the ward with self-catering facilities
  - Subsidised meals in the hospital café /staff cafeteria
  - Laundry facilities for the parent/carers of long stay patients
  - Washing and showering facilities.

5.4 Surgery

- Surgery should be provided on dedicated lists with identified anaesthetists allocated to children's surgery.
- All children should have the right to have their parents/carers stay with them until anaesthetised prior to surgery, and to be present in the recovery room after surgery.

5.5 Education and play

- All children and young people, whether admitted to children's wards or adult wards, should have access to:
  - Education provision no longer than five days after admission, irrespective of the location of the hospital relative to the local authority area where the child normally resides (assuming the child's health makes this appropriate)
  - Provision of education immediately if it is known on admission that the child will be in hospital for longer than five days
  - Qualified play staff and recreational facilities appropriate to age and development.

5.6 The role of the Child Health Commissioner

- There needs to be clarity about the role of the Child Health Commissioner and consistency across health boards. To this end, the Child Health Commissioner must:
  - Have a clear job description
  - Take the lead in the development of the Child Health Strategy, planning and commissioning child health services
  - Have appropriate information systems in place to ensure the provision and monitoring of child health services.

Survey Report

6 Background and objectives

6.1 Background

Action for Sick Children Scotland (ASCS) is a registered Scottish charity which aims to improve standards in healthcare provision for children and young people. Underpinning its work is its desire for children, young people and their families to have greater involvement in decisions about the shape of health services for children and young people in Scotland. A key aspect of its work is promoting high quality healthcare services for children and young people, including equality of services and service access across Scotland.

In particular ASCS:

- Works with the Scottish Government, NHS and voluntary sector to ensure that health services are planned for sick children and young people in child-centred environments equipped with appropriate ratios of trained staff.
- Informs children and young people, parents and carers of their rights and responsibilities, where to access advice and support and what they should expect from health service providers – empowering them to participate in decisions about the treatment and care of their child.
- Raises awareness and represents children and young people's needs and concerns within government, healthcare committees and other non-governmental organisations.
- Promotes the use of evidence-based practice to provide high quality healthcare services at home and in hospital, while working to obtain equality of services and access across Scotland.

Key standards for paediatric care are the articles of the European Association for Children in Hospital (EACH) Charter. EACH is an umbrella organisation for member countries involved in the welfare of all children before, during and after a hospital stay. The EACH Charter sets out ten articles which represent good practice in delivering healthcare services for children and young people as well as in delivering family centred care.

Underpinning the EACH Charter is the United Nations Convention on the Rights of the Child (UNCRC). This is the first legally binding international instrument to incorporate the full range of human rights; civil, cultural, economic, political and social rights. In 1989, world leaders decided that children needed a special convention because people under 18 years of age often need additional care and protection of a different order to that of adults.

The Convention sets out the basic human rights that children everywhere have. These are based on four core principles of non-discrimination, devotion to the best interests of the child, the right to life, survival and development and respect for the views of the child.

The Scottish Government also acknowledges the importance of the EACH Charter and UNCRC in its children's strategy "Delivering a Healthy future: An Action Framework for Children and Young People in Scotland" (Scottish Executive 2007) http://scotland.gov.uk/Resource/Doc/165782/0045104.pdf which sets out actions required to be taken forward by healthcare and health services to deliver effective child and family-centred services to ensure improvements in the health of children and young people.

6.1.1 The EACH Charter articles

The ten articles of the EACH Charter, which the Scottish Government has committed to, are outlined below. Full details of all the articles, including their sub clauses, can be found in Appendix 1.

ARTICLE 1 Children shall be admitted to hospital only if the care they require cannot be equally well provided at home or on a day basis.

ARTICLE 2 Children in hospital shall have the right to have their parents or parent substitute with them at all times.

ARTICLE 3 (1) Accommodation should be offered to all parents and they should be helped and encouraged to stay.

(2) Parents should not need to incur additional costs or suffer loss of income.

(3) In order to share in the care of their child, parents should be kept informed about ward routine and their active participation encouraged.

ARTICLE 4 (1) Children and parents shall have the right to be informed in a manner appropriate to age and understanding.

(2) Steps should be taken to mitigate physical and emotional stress.

ARTICLE 5 (1) Children and parents have the right to informed participation in all decisions involving their health care.

(2) Every child shall be protected from unnecessary medical treatment and investigation.

ARTICLE 6 (1) Children shall be cared for together with children who have the same developmental needs and shall not be admitted to adult wards.

(2) There should be no age restrictions for visitors to children in hospital.

ARTICLE 7 Children shall have full opportunity for play, recreation and education suited to their age and condition and shall be in an environment designed, furnished, staffed and equipped to meet their needs.

ARTICLE 8 Children shall be cared for by staff whose training and skills enable them to respond to the physical, emotional and developmental needs of children and families.

ARTICLE 9 Continuity of care should be ensured by the team caring for children.

ARTICLE 10 Children shall be treated with tact and understanding and their privacy shall be respected at all times.

Note: The EACH Charter definition of a parent substitute (see Article 2 above) is any person, other than the child's parent, who has responsibility for caring for that child e.g. foster parent, relative, legal guardian.

6.2 Definition of a child

The United Nations Convention on the Rights of the Child (UNCRC) is a comprehensive, internationally binding agreement on the rights of children, adopted by the UN General Assembly in 1989. A child is defined in the UNCRC as a person under the age of 18 years.

A child is defined in several ways in Scottish legislation. For the purposes of those provisions focusing explicitly on the UNCRC which are included in the Government's Children and Young People (Scotland) Bill, a child is considered to be any individual up to the age of 18. However, the Children (Scotland) Act 1995 identifies certain parental responsibilities and rights, including safeguarding and promoting a child's health, as only applying to children under the age of 16.

In this report, we have used the terms child up to 12 years and young person, rather than adolescent, when referring to 13-18 year olds.

6.3 Research objectives

In support of its work, ASCS has received funding from the Scottish Government to conduct surveys assessing the extent to which hospital services meet national and international standards of "good" paediatric care.

Six surveys have been conducted since 1985, the results of which have been used by the Scottish Government and local health boards in planning service delivery and by ASCS to encourage service development and inform parents/carers of the availability of services for children and young people in local hospitals.

ASCS commissioned its seventh, Scottish Government funded survey, in order to:

- Identify and profile current parental access and family facilities in Scottish hospitals
- Highlight progress made and compare provision against EACH standards
- Highlight elements of good practice in accessibility, service provision and facility provision
- Identify aspects in which current provision does not meet expectations.

The research methods adopted to achieve these objectives are outlined in Appendix 2.

7 Profile of parental access and family facilities

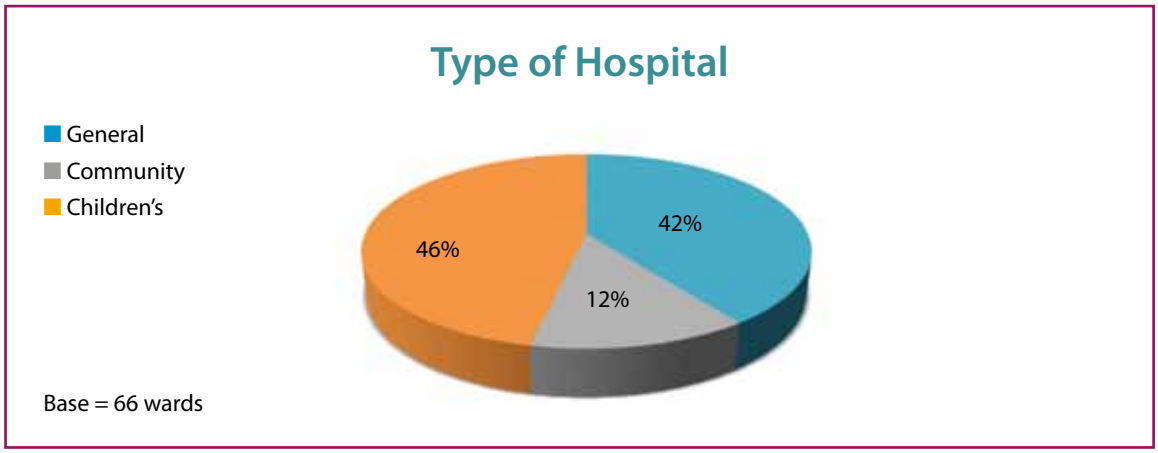
Email invitations were issued in October 2012 to a total of 85 hospital wards across Scotland which had been identified by senior nursing management at the health boards as admitting children and/or young people. Following completion of an on-line survey and a telephone follow-up, a total of 66 questionnaires was completed, resulting in a response rate of 77.6%. Additionally, visits were conducted to six hospitals to explore parents' experiences of visiting their child in hospital and staff experiences of providing care. The information gained from these visits was not used in the analysis which follows but is set out separately in Section 8.

A second questionnaire was sent to the Child Health Commissioner in each health board with a request for an overview of the current services for children and young people in their area and questions covering areas such as the numbers of admissions of children in particular age groups (and the facilities available for them), numbers of play and teaching staff employed and availability of paediatrically trained staff. Only 7 out of 14 Child Health Commissioners responded to the survey and the quality of the data they provided was not sufficient for analysis and have not therefore been included in this report.

7.1 Profile of respondents

The 66 responses comprised:

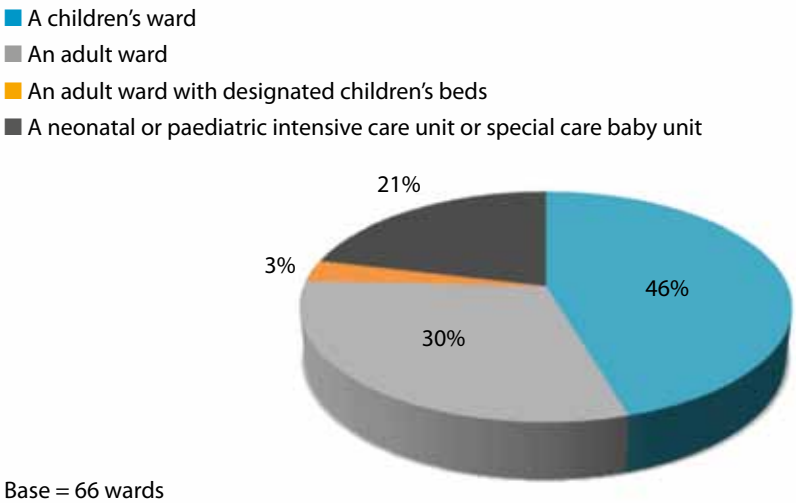
- Children's wards (30 out of 66 wards)
- Adult wards admitting children/young people (20 out of 66 wards)
- Adult wards with a children's annexe (2 out of 66 wards)
- Neonatal, paediatric intensive care or special care baby units (14 out of 66 wards)



The respondents tended to be working in either general hospitals or children's hospitals and represented all of the 14 health board areas.

Non-respondents were from adult wards in general hospitals which admitted children and from accident and emergency areas in general hospitals.

Type of Ward Surveyed (Q1)



Base = 66 wards

7.2 Participating Hospitals and Health Boards

Arran War Memorial	Ayrshire & Arran
Ayrshire Maternity Unit	Ayrshire & Arran
Balfour Hospital	Orkney
Borders General Hospital	Borders
Campbeltown Hospital	Highland
Canniesburn Unit, Glasgow Royal Infirmary	Greater Glasgow & Clyde
Dr Grays Hospital – Elgin	Grampian
Dumfries & Galloway Royal Infirmary	Dumfries & Galloway
Forth Valley Royal Infirmary	Forth Valley
Gilbert Bain Hospital	Shetland
Lorn & Islands District General Hospital	Highland
MacKinnon Memorial Hospital	Highland
Mid Argyll Community Hospital & Integrated Care Centre	Highland
Monklands District General Hospital	Lanarkshire
Ninewells, Tayside Children's Hospital	Tayside
Perth Royal Infirmary	Tayside
Princess Royal Maternity Hospital	Greater Glasgow & Clyde
Raigmore District General Hospital	Highland
Royal Aberdeen Children's Hospital	Grampian
Royal Alexandra Hospital	Greater Glasgow & Clyde
Royal Hospital for Sick Children Edinburgh	Lothian
Royal Hospital for Sick Children Glasgow (Yorkhill)	Greater Glasgow & Clyde
Southern General Hospital	Greater Glasgow & Clyde
St Brendan's Hospital	Western Isles
St John's Hospital	Lothian
University Hospital Ayr	Ayrshire & Arran
University Hospital Crosshouse	Ayrshire & Arran
Uist & Barra Hospital	Western Isles
Victoria Hospital	Fife
Western Isles Hospital	Western Isles
Wishaw District General Hospital	Lanarkshire

7.2.1 *Children and young people up to the age of 18*

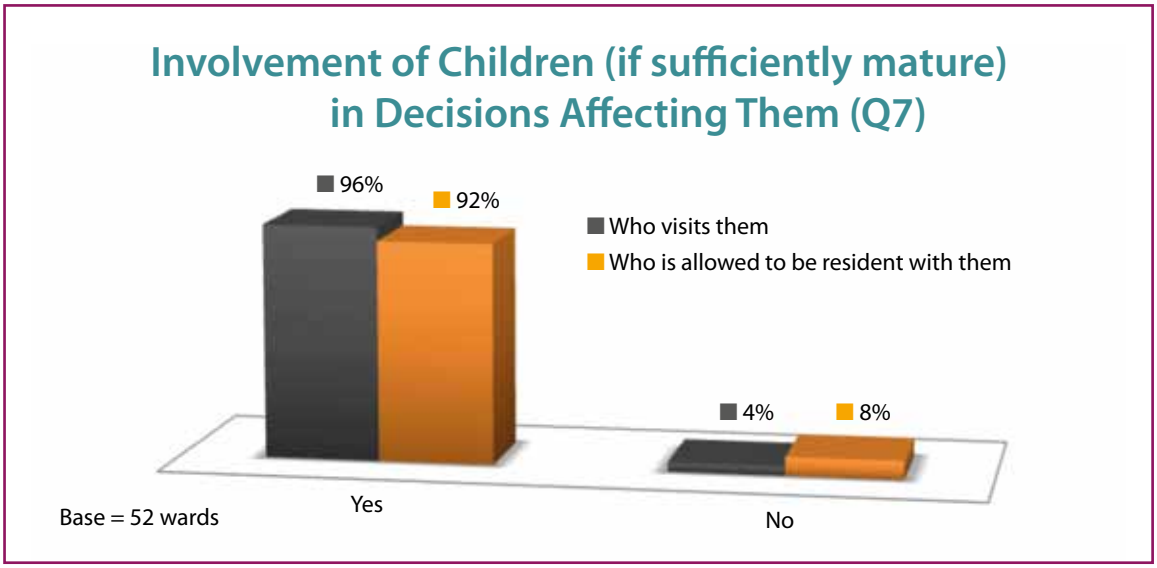
Few of the children's wards indicated that they admitted young people between the ages of 17 and 18. The adult wards tend not to record the number of admissions of young people aged 17-18 – these patients were included in the overall adult admission figures for the wards. As a result only 540 in-patients aged 17-18 were reported as having been admitted to the wards annually (representing information from 16 wards).

Only 56% of the respondents were able to provide details of how many children under the age of 16 were admitted annually, either as day cases or as in-patients. This amounted to 58,105 children. Only 15% of these children were seen as day cases.

Information obtained from the Information Services Division (ISD) of NHSiS shows that 99,646 children up to the age of 14 and 25,101 15-18 year olds were admitted to hospitals in Scotland in 2011/12 – suggesting that the information on admissions provided by participating wards reflects about half of the actual admissions of children and young people across Scotland. This is due in part to the way in which hospitals and health boards monitor their admissions as noted above. The overall response rate to the questionnaire of 77% provides reassurance that the data presented in the following sections relates to substantially more than half the annual Scottish hospital population of children and young people.

7.3 Parental access

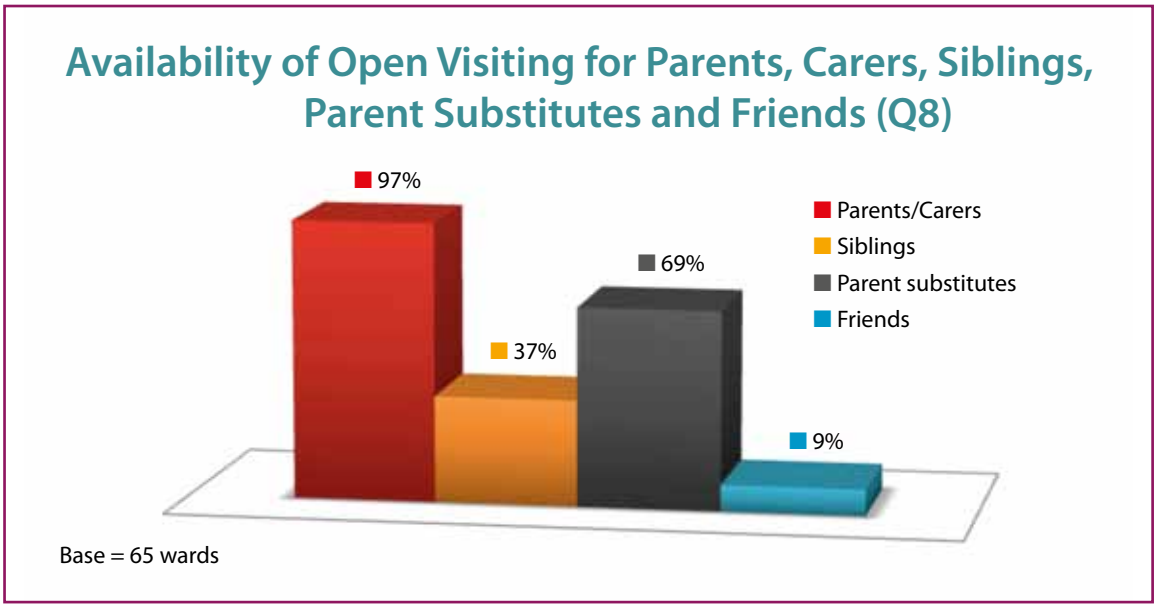
7.3.1 Having a say



Of 52 wards (children's and adults and excluding neonatal), 96% indicated that children, if they were sufficiently mature, are encouraged to have a say in who visits them and 92% have a say in who is allowed to be resident with them. The wards that do not allow this were in either general or community hospitals.

In most cases this information is recorded either in the care plans or in the nursing notes. However, there are a small number of wards in general hospitals where the information is not recorded.

7.3.2 Visiting arrangements



All but three of the 65 wards have open visiting for parents or carers (one ward did not complete this question). The wards with restricted visiting are adult wards in general hospitals. Almost three quarters of the wards (69%) have open visiting for parent substitutes. Wards with restrictions for parent substitutes tend to be general or community hospitals or neonatal/ paediatric intensive care/special care baby units. Visiting for parent substitutes is more restricted in neonatal wards. Less than a third (29%) of neonatal wards have open visiting for parent substitutes.

Even where there are open visiting arrangements in place, there are some restrictions in parents/carers visiting during school lessons (20%), doctors' rounds (12%) and rest hour (11%). The restrictions apply irrespective of ward or hospital type.

It should also be noted that, whilst the neonatal wards have open access for parents, half of these wards (50%) restrict visiting during doctors' rounds due to lack of space between cots and concerns about confidentiality during doctors' rounds.

Visiting arrangements for siblings and other visitors are more restricted. Sibling visiting appears to vary depending on the health of either the child (visiting being restricted where the child was very ill) or the amount of space in the ward which is often limited in more specialist wards such as High Dependency and neonatal wards. On-site facilities for siblings who are unable to visit appear limited with only four wards indicating that that they have crèche facilities available.

Visiting for friends is also more restricted. Approximately half the wards (46%) offer visiting for limited hours and a third of wards (30%) offer variable times by agreement. In the case of limited hour visiting, this tends to be for two hours in the afternoon and two hours in the evening.

All but one of the wards afford both parents the opportunity to visit at the same time. The ward which does not is limited by space.

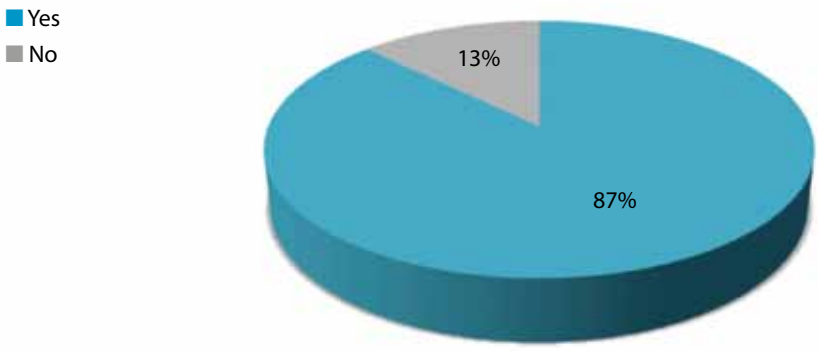
However, only half of the wards can accommodate both parents overnight and in the case of neonatal wards or special care baby units, this reduces to a third (33%). Lack of available space appears to be the key reason for this. Many of the wards only have space for one z bed at the bed side and have only limited accommodation available off the ward.

7.4 Parental facilities and accommodation

7.4.1 Accommodation

The wards offer a total of 353 single rooms or cubicles. This varies between a third and a half of the number of beds available in each of the children's wards. Eighty of the single rooms were available in adult wards.

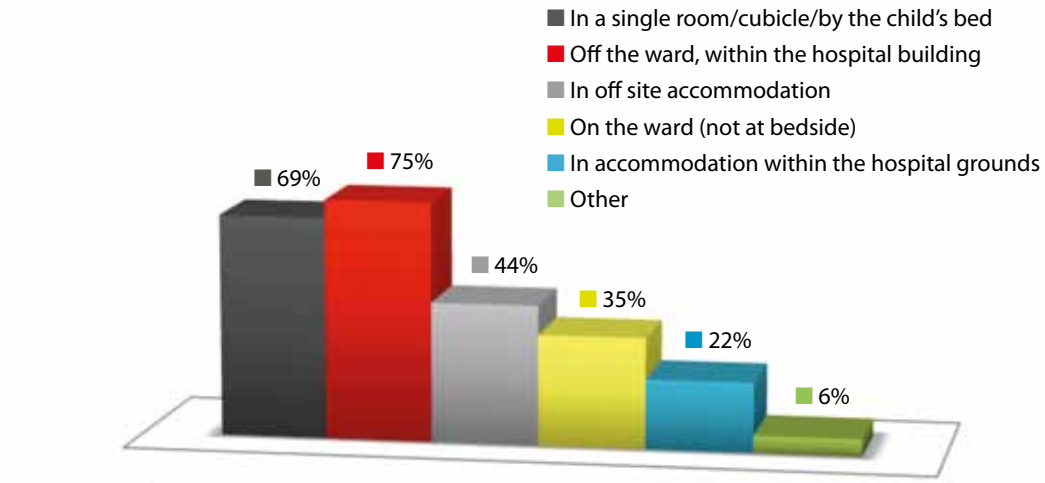
Overnight Stay for Parents/Carers (Q13)



Base = 63 wards

Although the vast majority of wards allow a parent or carer to stay overnight, 13% do not (three of these are adult wards). Half of those that do not provide overnight accommodation are in general hospitals with the remainder in community or children's hospitals. These wards tend to have limited space available. Just over one in ten wards (13%) has also had to turn a parent away due to lack of accommodation. These tend to be neonatal or special care baby units.

Sleeping Arrangements for Parents/Carers (Q15)



Base = 55 wards

The above chart relates to those wards which report that overnight accommodation is provided for overnight stays for parents/carers.

Wards where overnight accommodation is available generally operate a variety of sleeping arrangements. Two thirds of wards (65%), including neonatal wards, can accommodate parent/carers on the open ward and 60% in a single room or cubicle by the child's bed. On the ward, half of parents (51%) use z beds and 40% armchairs. 15% of wards use empty beds (these were general or community hospitals). Less than half of the wards (46%) have space for a fold down or z bed by every cot or bed.

Wards may offer more than one type of accommodation. 44% of wards offering parental accommodation provide it elsewhere in the hospital and 22% provide it elsewhere in the hospital grounds. Almost all of the wards which have a High Dependency Unit (83%) could allow a parent or carer to sleep nearby. This tends to be in armchairs or in parent accommodation close to the wards.

Despite the majority of wards offering accommodation to parents/carers, less than half (46%) make information on accommodation available to parents in their pre-admission paperwork. Neonatal wards and special care baby units are more likely to provide this information with 70% supplying information on accommodation to parents/carers before admission.

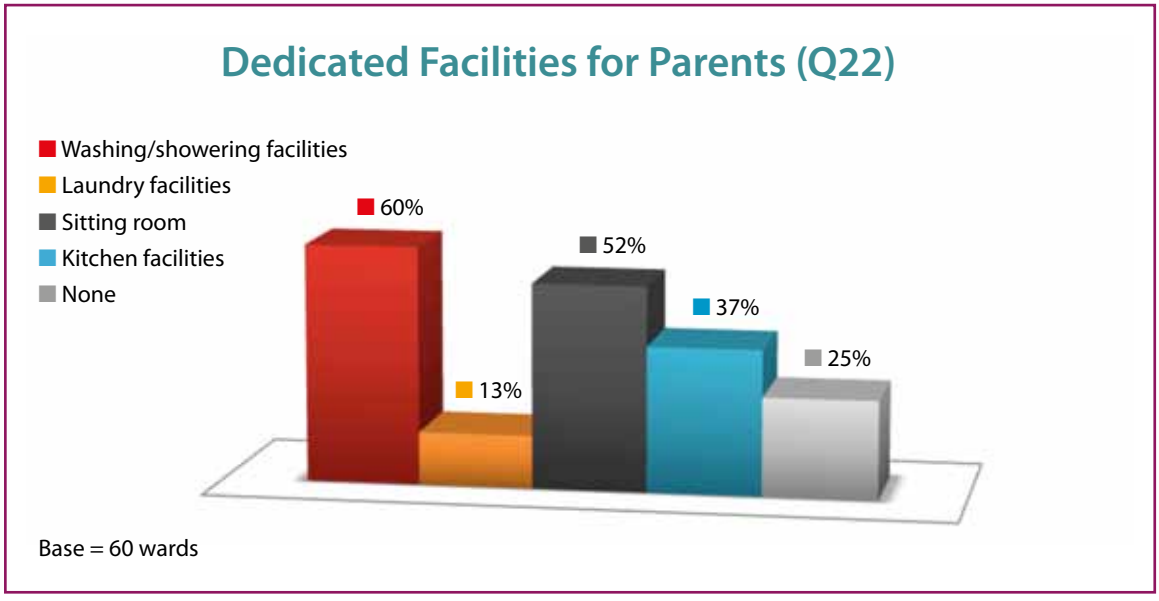
Almost three quarters (70%) of neonatal wards or special care baby units offer single rooms/ cubicles to parents/carers but only a fifth have space for parents/carers to sleep in a z bed next to the cot.

Three quarters of neonatal wards or special care baby units (71%) can offer parents accommodation close to the ward. However, if accommodation close to the neonatal wards or special care baby units could not be found, only 27% can offer parents the option of staying close by.

The neonatal wards indicated that no parent is ever turned away – wards would endeavour to accommodate the parent somewhere. Restrictions in space meant that 60% of neonatal wards or special care baby units could only accommodate one parent.

44% of the wards are able to offer accommodation to a sibling. These wards tend to be children's wards in children's hospitals. Only a third of neonatal wards or special care baby units can accommodate a sibling due to space restrictions.

7.4.2 Facilities



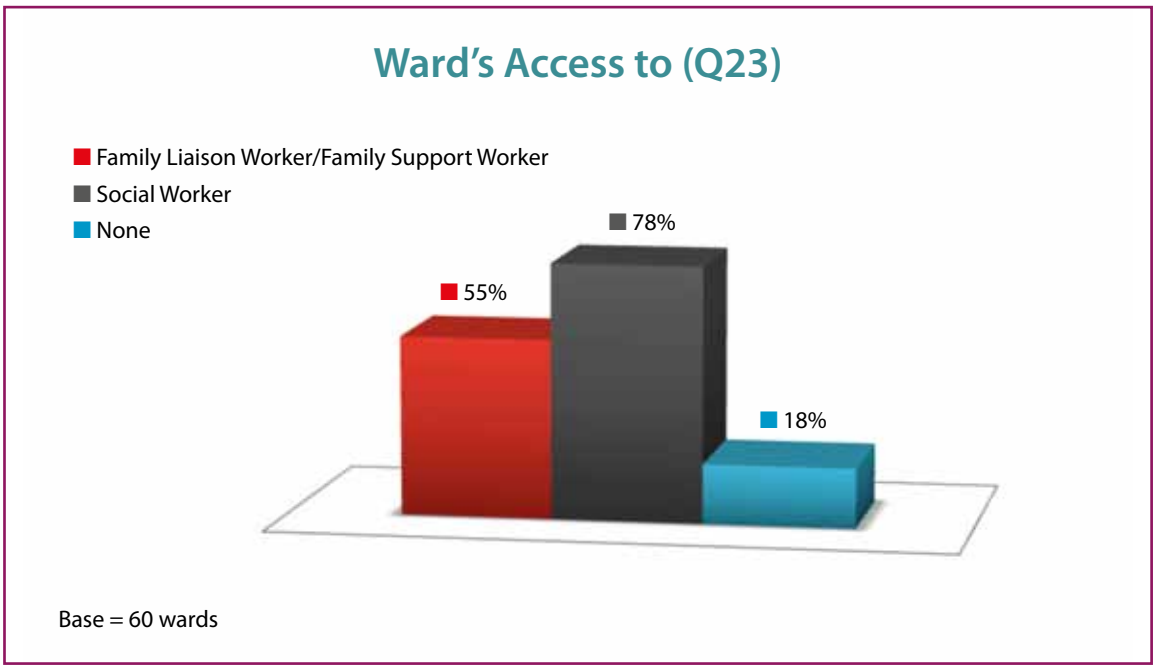
60% of all wards have washing or showering facilities for parents/carers. Two thirds of these are children's wards. The majority of adult wards do not have washing or showering facilities for parents/carers while two thirds (67%) of neonatal wards or special care baby units do have washing facilities.

Just over half of all the wards (52%) have a parents' sitting room. Two thirds of these are children's wards. 56% of neonatal or special baby units have a parents' sitting room. Few adult wards offer sitting rooms.

Only 37% of all wards have kitchen facilities and only 13% have laundry facilities for parents/carers. However, neonatal wards or special care baby units were more likely to have kitchen facilities (67%), although none have laundry facilities.

A quarter of wards (25%) have no dedicated facilities for parents/carers at all. Almost all of these are adult wards, although three children's wards indicated that they had no dedicated facilities for parents/carers.

7.4.3 Family support



Just over three quarters of the wards (78%) indicated that their ward has access to a social worker. However, access to other support is much more limited. Just over half (55%) of all wards have access to a family liaison worker or family support worker. Almost one in five wards has no access to any support. These were both children's wards and adult wards.

Neonatal wards or special care baby units are more likely to have access to family support. 89% have access to a Social Worker and 78% to a Family Support Worker.

Almost all the wards other than neonatal and special care baby units (92%) offer children and young people access to spiritual care. Those wards which do not are in general or community hospitals. Only 56% of neonatal wards or special care baby units have access to spiritual care.

90% of wards offer bereavement facilities for families. The overwhelming majority offer access to a chaplain. One in five wards (in children's hospitals) also offer access to a specialist support group.

Just over two thirds of wards (70%) operate a named nurse policy. Half of those who do are adult wards with the remaining half in children's wards in one health board area. However, it should be noted that only 56% of neonatal wards or special care baby units operate a named nurse policy.

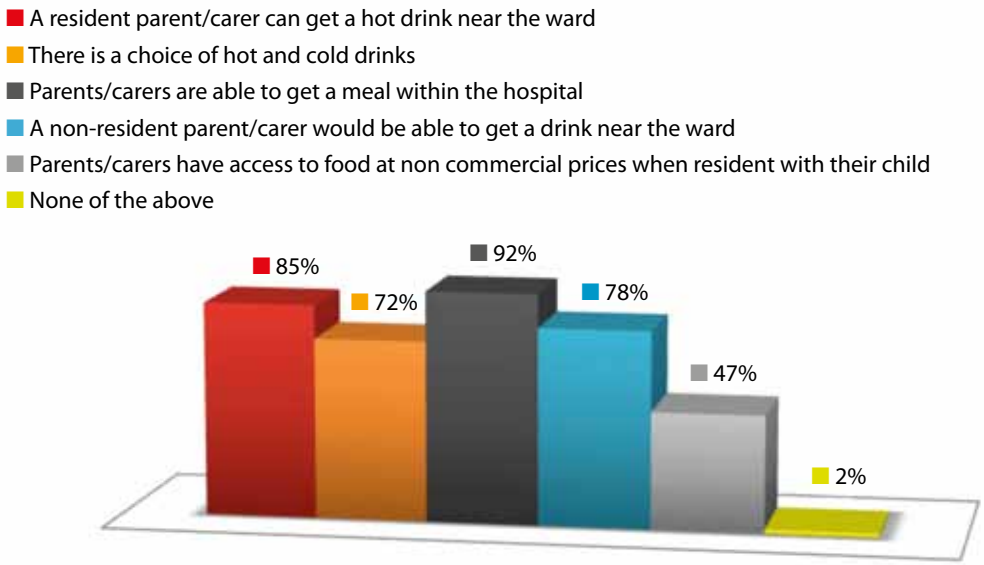
One of the children's hospitals offers families access to a family support centre which helps families with a variety of issues including financial support, benefits advice and signposting to other services.

92% of wards provide leaflets for families with information on admission procedures, ward routines and visiting arrangements. Some of this information is sent out with admission documentation whilst some is available on the ward or at the bedside.

Only one in three wards offer parents access to the internet or email. These were either in general or children's hospitals and tend to be in urban rather than rural locations. Only a fifth (22%) of neonatal wards or special care baby units offer parents internet or email access.

7.4.4 Refreshment and meals

Refreshment Options for Parents/Carers (Q30)



Base = 60 wards

The overwhelming majority of resident parents can get a hot drink (85%), a choice of hot and cold drinks (72%) and a meal within the hospital (92%). All of the neonatal wards or special care baby units offer these to parents/carers.

Non-resident parents could also get a drink near the ward (78%).

However, less than half of wards (47%) provide parents and carers with access to food at non-commercial prices. Those that do, tend to be wards in general hospitals.

In addition to this, a third of all wards (31%) do not provide meals for breastfeeding mothers (56% of neonatal wards or special care baby units do).

The data from the survey suggested that the overwhelming majority of wards offer the following for parents/carers and siblings:

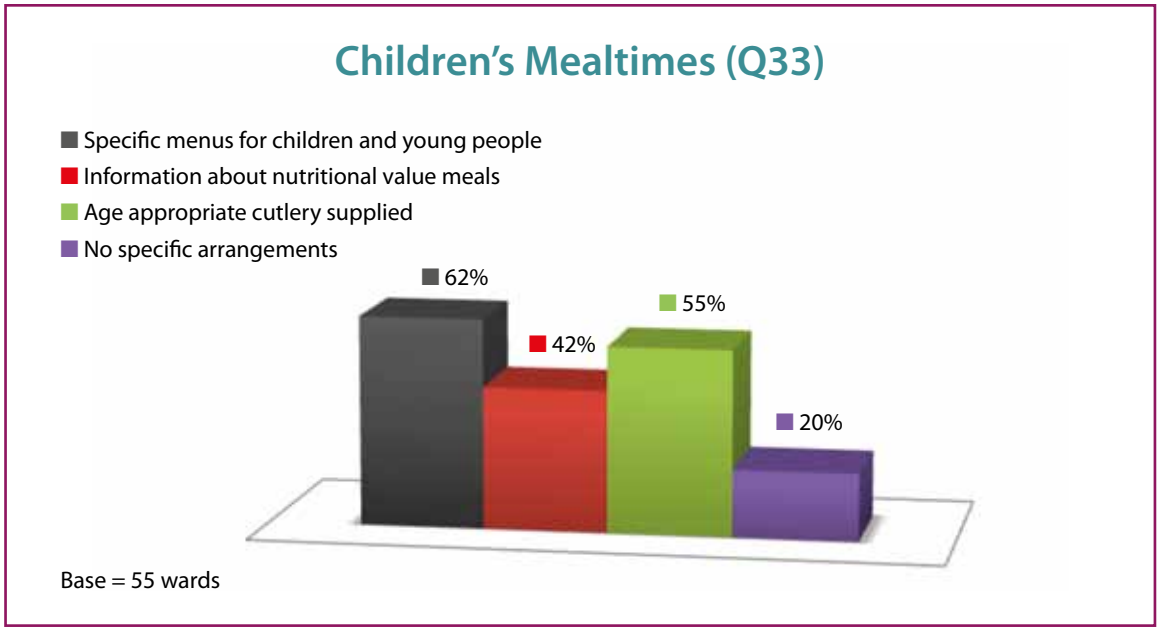
- Use of staff canteen (95%)
- Vending machines (87%)
- Café facilities (83%).

Just over half (52%) offer a sitting room for parents/carers and 53% offer this for siblings. Few wards offer parents/carers or siblings self-catering facilities and only the vending machines tend to be available out of hours.

7.4.5 Children's meal times

Two thirds of wards (62%) have specific menus for children/young people. Only 55% supply age appropriate cutlery and tableware, and less than half (42%) supply the nutritional value of their meals. One in five wards does none of this. These wards tend to be adult wards in general hospitals but one ward is a children's ward. All wards report that they provide support to children who are unable to feed themselves if their parents/carers are not available.

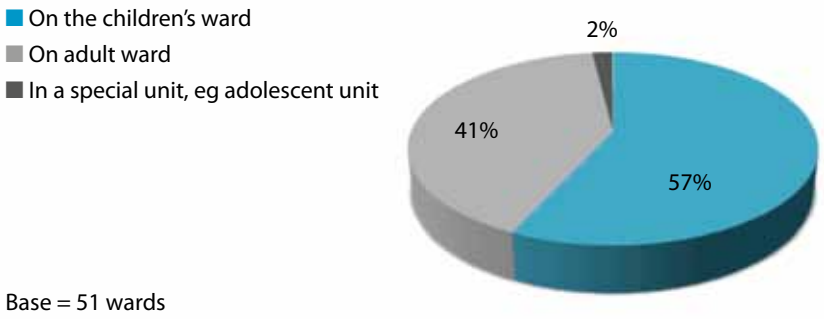
Only one ward was able to indicate the daily spend per child on children's meals (£1.67 per day). This information appears not to be generally available to ward staff.



7.5 Young people's services

57% of the wards accommodate children aged 12 and above on the children's wards. Half of these wards accept children up to the age of 14 and the remainder accept children up to the age of 16. Only one hospital (a children's hospital) accommodates 14 to 16 year olds in a 6-bedded adolescent unit, the remainder (41%) place these patients in adult wards. However, exceptions are made for young people with complex health issues or who are undergoing regular treatments for chronic conditions. These patients are accommodated on children's wards irrespective of age.

Accommodation Arrangements for Young People over 12 years (Q36)



Base = 51 wards

Two thirds of the adult wards (64%) have facilities for the parents/carers of young people with profound disabilities to stay with them. Only 2 out of 51 wards have a youth worker.

A clear majority of wards:

- Offer young people advice about their treatment (92%)
- Involve young people in decisions about their treatment (90%)
- Allow young people's friends to visit (85%)
- Offer young people information about confidentiality and consent (83%)
- Allow young people to use mobile phones (81%).

But less than half the wards (45%) provide internet access for young people.

Approximately three quarters of wards (73%) offer young people information about how to make a complaint.

Two thirds (65%) allow a parent/carer to stay when on an adult ward.

Only 13% of wards offer children aged 14 -18 a choice of children's or adults' wards or give them a choice of a same sex ward or mixed sex bay.

Just over three quarters of wards (77%) allow young people to consent in their own right and allow young people to be seen without their parents present.

Only three wards were planning any changes to young people's care. These were children's wards planning an expansion to the ward.

7.6 Ambulatory care, short stay and surgery

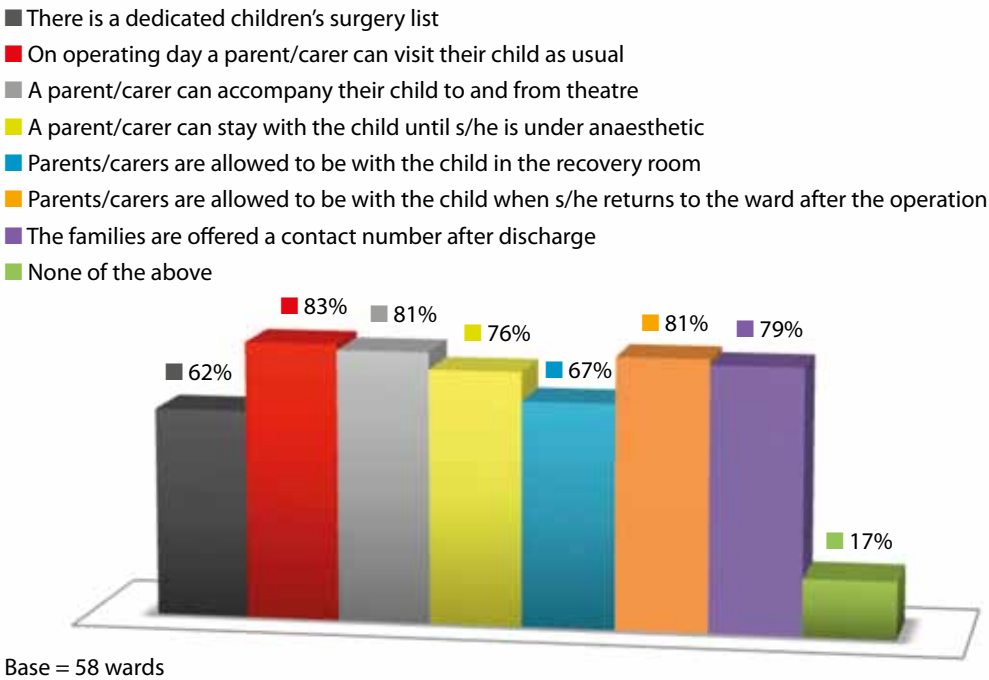
Less than half of the wards (46%) provide ambulatory care. The wards which do, tend to be in general or community hospitals.

38% of wards reported that they provide community children's nursing. These tend to be children's wards in general hospitals. Given that each Health Board in Scotland (except NHS Grampian) has community nursing, this appears to reflect substantial under-reporting and might relate to lack of knowledge of the child's home area or community support.

Roughly two-thirds of wards (62%) admit children and young people for day case procedures and a third (34%) have a short stay ward. Again, these tend to be children's wards in general hospitals. Of these, 71% have access to play specialists.

57% of all wards have identified anaesthetists allocated for children's surgery. Half of the neonatal wards or special care baby units and 21% of the adult wards have identified anaesthetists. Half of the neonatal wards or special care baby units, just under half (46%) of the general hospitals and 75% of the community hospitals do not have anaesthetists identified for children's surgery. However, it should be noted that these figures may include wards which do not undertake surgical procedures in children.

Operating Day (Q53)



Base = 58 wards

Almost two thirds (62%) of all responding wards and 63% of neonatal wards or special care baby units have a dedicated children's surgery list. Those that do not are general hospitals and community hospitals.

The majority of the wards allowed the parents/carers to:

- Visit on operating day (83%)
- Accompany their child to and from theatre (81%)
- Stay with their child until they were under anaesthetic (76%)
- Be with the child when they return to the ward (81%).

Two thirds of wards (67%) allow parents/carers to be in the recovery room with their child.

However, parents were less likely to be afforded these opportunities in neonatal wards or special care baby units. Only 63% of these wards allow parents/carers to visit on the operating day, accompany their child to and from theatre and be with their child on their return to the ward. Only 38% allow parents/carers to stay with their child until they are under anaesthetic and to be with them in the recovery room.

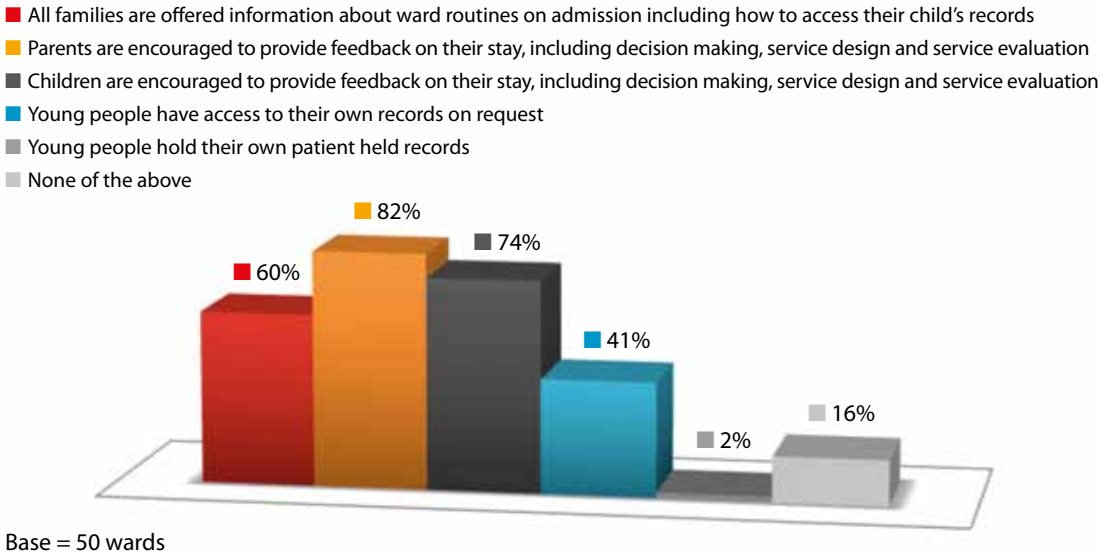
Approximately one in five of all wards and over a third of neonatal wards or special care baby units do not offer any of these opportunities to parents/carers.

43% of wards indicated that there was a dedicated day surgery ward in their hospital. These tend to be children's wards in general hospitals.

Just over one in three quarters of wards (79%) offer families a contact number after discharge. Those that do not were general hospitals and community hospitals.

7.7 Records and feedback

Information, Records & Feedback (Q55a)



Base = 50 wards

Almost all wards encourage parents to provide feedback on their stay and three quarters encouraged children to give feedback. However, less than half (41%) allow young people access to their own records and only one ward allows young people to hold their own patient records. Just over one in ten wards give families information on how to access their child's records but two thirds of neonatal wards or special care baby units do give families such information.

7.8 Other facilities

The majority of the wards have not undergone any changes to their facilities since 2007. The wards that had, tended to be children's wards with extensions to units and refurbishments of wards.

7.9 Travel

88% of all wards and 89% of neonatal wards or special care baby units offer parents information on travel expenses. Most of the information tends to be available at hospital rather than ward with less than half (41%) having information available on the wards.

7.10 Education

This section applies to 52 wards in the survey: 30 children's wards and 22 adult wards that admit children, whether into designated children's beds or not. Fifteen (15) of the 22 adult wards do not provide access to teaching – stating that most of the children were only admitted for short stays and therefore not eligible for education. In addition to this, 7 adult wards did not provide any information about education opportunities for children and young people.

All of the children's wards provided some information about education, indicating that all provide education for children or young people in some form or other. Of the 22 wards that answered the relevant question (58a), the teacher providing education was hospital-based in 18 wards and local authority-based, or from the child's school, in 4 wards.

Eight (27%) of the children's wards do not provide access to a teacher for children and young people admitted to the hospital from local authority areas other than where the hospital is situated.

Of the 21 children's wards that answered the question 'how many days after admission does teaching start', 5 (24%) gave a figure of 5 days or less (consistent with Scottish Government guidance) and 15 (71%) indicated that teaching would be requested after 7 days. Length of stay appeared to be the only criterion for accessing teaching.

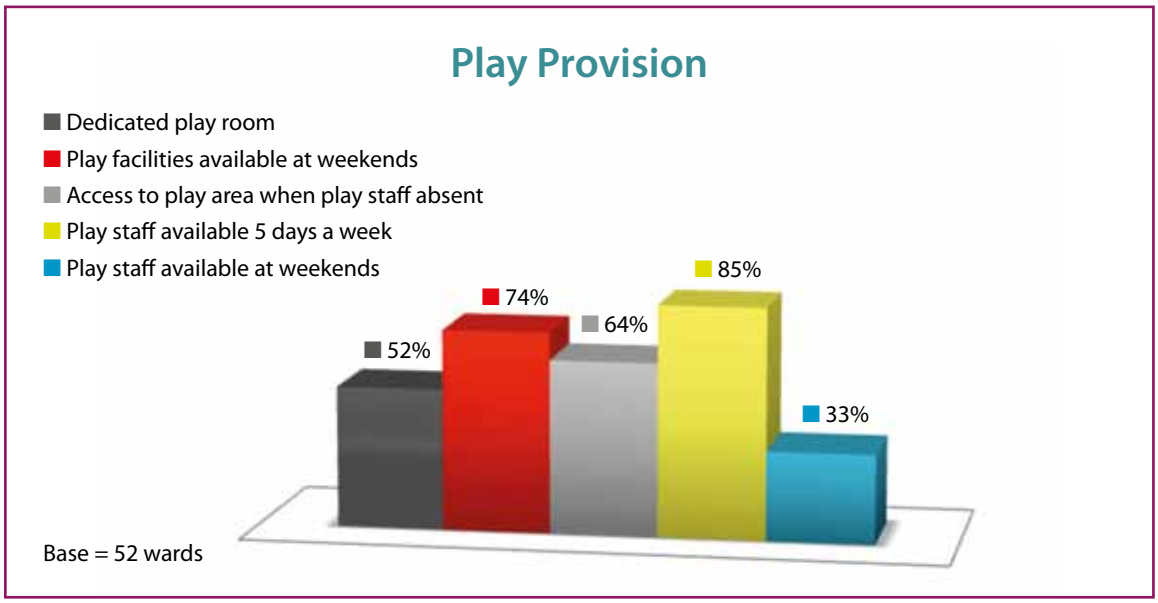
The overwhelming majority of wards were unable to provide details on how much time is spent in education per day per child and only 15% of wards have access to careers advice.

Two thirds of wards did not provide details on the breakdown of teaching staff hours. Hospitals that could provide this data tended to be children's hospitals which have qualified teachers working full time and part time across all nursery and school ages.

Only a quarter of children's wards have a dedicated classroom facility for either nursery, primary or secondary school aged children and only 30% of them have an additional support needs teacher available. These wards tend to be in children's hospitals.

Only two wards, both children's wards, indicated any plans to change education provision. These wards were seeking access to a full time teacher.

7.11 Play



Of 52 wards responding, three quarters (74%) have play facilities and equipment available at weekends (this excludes neonatal wards). Wards that did not, tend to be adult wards in general hospitals. Two thirds of wards (64%) have a play area which is accessible to parents when the play leader/specialist is not present. Again those that do not, tend to be adult wards in general hospitals.

A third of wards (32%) reported having a trained hospital play specialist (now called a health play specialist) dedicated to their ward and slightly more wards (38%) have one who is shared with other wards (these figures exclude neonatal wards).

Approximately one in five wards (18%) have a dedicated play assistant whilst the same number share a play assistant with other wards (18%). Few wards have nursery nurses either dedicated (12%) or shared (6%).

The majority of children's wards (85%) have a play staff member for at least five days per week. However, only a third has them available seven days per week. Adult wards reported no play provision.

The availability of play staff varied with a third of children's wards only having play staff available for half days. The numbers of play staff also varied with half of the wards having only one or two staff available to them.

Just over half of wards included siblings in the play. These tend to be in children's hospitals and some children's wards in general hospitals.

Opportunities for Play (Q72)

	Babies	Children	Young People	N/A**
Play preparation	61%	65%	61%	30%
Distraction therapy	70%	70%	65%	24%
Post-procedural play	65%	63%	61%	28%
Full Range of play*	61%	61%	59%	33%
Pre-admission visits*	54%	59%	61%	35%

Opportunities for play expressed as a percentage of the 46 wards which responded

**Supervised and appropriate for age and stage of development*

***The wards which responded N/A were generally adult wards where the respondent thought the questions were not relevant since the wards did not offer play opportunities*

Two thirds of wards (65%) provide play preparation (preparation for clinical procedures through play) for children and 61% provide it for babies and young people. Adult wards in general hospitals do not provide it at all.

70% of wards provide distraction therapy for babies, children and young people. Those that do not tend to be adult wards in general hospitals. It should be noted that only three out of 14 neonatal wards or special care baby units provide distraction therapy. Those that do not stated that it is not appropriate as the babies were too ill.

Two thirds of wards provide post-procedural play for babies, children and young people. Again those that do not tend to be adult wards in general hospitals.

The play opportunities for babies, children and young people with additional support needs are confined to children's wards and include soft toys, soft play areas and sensory toys/rooms.

58% (excluding neonatal wards) have a dedicated play room. These are children's wards in general and children's hospitals. Where there is a dedicated play room it is available all day every day. Adult wards do not have a dedicated play room.

70% of wards have play facilities available to parents. Just over half of wards allow children to use the room unsupervised.

Few wards are planning to change their play facilities. Two wards are planning an upgrade to their adolescent facilities and one children's hospital is seeking to increase its play staff to allow it to increase its play provision.

8 Parents' lived experiences

8.1 Background

Visits were conducted to six hospitals to explore parents/carers' experiences of visiting their child in hospital and staff experiences of providing care. The hospitals selected were as follows:

- Borders General Hospital: a children's ward in a general hospital serving a rural location
- University Hospital Crosshouse: children's wards in a children's unit in a general hospital serving urban and rural locations
- Dumfries and Galloway Royal Infirmary: a children's ward in a general hospital serving a rural location
- Ninewells, Tayside Children's Hospital: children's wards in a children's unit in a general hospital serving urban and rural locations
- Royal Aberdeen Children's Hospital: a specialist children's hospital serving urban and rural locations and also accepting referrals from Island Health Boards
- Royal Hospital for Sick Children Glasgow: a specialist children's hospital serving urban and rural locations and also accepting referrals from across Scotland for specialist care.

Discussion guides were agreed with the ASCS project team to explore experiences with parents and staff. Copies of these guides can be found in Appendix 4.

Parents and staff were asked by the researcher visiting the ward if they wished to participate in the research. Participation was entirely voluntary and only parents and staff who gave their consent to take part, were interviewed. Their feedback is anonymised to protect the identity of both the parent and their child. The observations which follow in the remainder of section 8 apply to all the hospitals visited.

8.1.1 Ward environments and facilities (based on observation)

Visiting the wards offered the researcher the opportunity to see the ward environments first hand. All the wards were bright and pleasantly decorated. There were colourful posters and drawings throughout the communal areas and there were information notice boards and leaflet boards in various locations in the ward areas. The EACH Charter standards were also prominently displayed in several locations through the wards.

The wards all have a sitting room area for parents with tea and coffee making facilities, microwaves and fridges.

8.1.2 Catering facilities

In general, parents are not provided with meals on the wards. Staff did often provide parents with toast and cereals and parents also have access to the hospital canteens. In the majority of cases parents could not purchase meals at a discounted rate (in accordance with the survey's finding, reported in section 7.4.4, that less than half the wards provide food for parent/carers at non-commercial rates).

8.1.3 Accommodation

All the wards have fold-down (Z) beds for parents to sleep with their child in both the single rooms and in the larger bays. This allowed one parent to stay overnight with their child if required.

Young people tend to be accommodated on the wards in the same areas as younger children. There were few wards with a separate area for young people.

8.1.4 Play facilities

In each of the wards visited, there is a dedicated play room with play specialists, play assistants and volunteers. The play rooms have a selection of toys and games which can be used in the room or taken to the child's bedside. The majority of play items were for younger children, items for adolescents were more limited.

Staff perspective

Discussions were held with nursing and play staff at all hospitals visited and also the hospital teacher (University Hospital Crosshouse) and medical staff (Royal Aberdeen Children's Hospital). All of the staff interviewed had received paediatric specific training. In general, staff felt that they had a good relationship with parents and that parents are well supported on the ward, and are kept well informed about the ward and its routines.

Parents' perspective

Discussions were held with parents of children who were regularly admitted to the ward as well as with parents of children who had been admitted for the first time. The children included those who had been planned admissions as well as those who had been admitted as an emergency.

Awareness of the ward routines was best amongst parents who were either regular attenders on the ward or whose child was a planned admission. Parents of children admitted as an emergency were least informed about the ward and its facilities and relied on other parents to advise them. These parents were unaware of the availability of the ward information folder. As one parent explained:

> *"This is the first time my daughter has been in hospital. We came in as an emergency. I had no idea what to expect and, to be honest, was more concerned about (daughter's name) than anything else. I don't remember staff telling me anything and I've had to ask other parents to find out where things are."*

All parents interviewed had stayed overnight with their child, generally in a fold down bed at the child's bedside in a single room or in a chair at the bedside in a multi-bed bay. The single rooms have their own toilet area whereas parents who sleep in chairs in the bays need to use shared toilets. Some parents at the Royal Aberdeen Children's Hospital and Royal Hospital for Sick Children Glasgow had stayed in purpose-built accommodation off the ward.

All parents had been with their child to the ward's play area and were aware of the range of toys and games available. All suggested that they were happy with the arrangements for play for younger children but parents of older children at the Royal Aberdeen Children's Hospital, Royal Hospital for Sick Children Glasgow, and those of both older children and children with additional support needs at Borders General felt that the choice of games etc is more limited. Parents of older children and those with additional support needs felt that the play opportunities were more limited. As one parent explained:

> *"I know most of the children who will be in the ward will be very young but there are teenagers in it and there is really very little for them. It makes it a long day."*

A key issue for parents was accessing food for themselves during their stay. Parents were aware that they could access the hospital canteen but were reluctant to use it as this meant being away from their child for too long. As one parent commented:

> *"My wee girl is only five and she won't let me out of her sight."*

As a result, resident parents often rely on spouses and family members to bring food in for them or when this is not feasible, use vending machines or go without.

> *"I get toast from the staff in the morning and that keeps me going. My husband gets here at night so I try and nip out for something to eat when he is here."*

A parent whose child was an emergency admission commented:

> *"I've been running out to the shops nearby. I don't like leaving her but I've needed to get something to eat. We live two hours away and my husband can only get here at night."*

Another issue related to lack of laundry facilities for parents. Those parents who had to stay with their child for a number of days either took their laundry home (those who lived locally) or attempted to find local launderette facilities.

> *"I know it seems like a small thing but you've enough to think about with your child in hospital. I've ended up paying for my clothes to be cleaned in a laundry across the road."*

One parent of a child who was receiving long term treatment highlighted her feeling of isolation in the ward:

> *"I'm going to be here for weeks with (daughter's name). I find it really difficult because I am on my own with her in her room all day until my husband gets here at night. The staff pop in every so often but it would be great to have some contact with other parents."*

This feedback from the parents and the staff has not been included in the data analysis which is solely questionnaire based.

More extensive feedback and further information about the hospital visits, with background information on each of the hospitals, is contained in Appendix 5.

9 Comparison with the EACH Charter

Given that ASCS and the Scottish Government are committed to the EACH Charter, this report tests the results of this research against the relevant EACH articles relating to parental access and family facilities. Only the numerical data from the questionnaire has been used for this comparison. Article 1 of the Charter was not reviewed in this survey and is therefore omitted from this report.

9.1 Article 2: Children in hospital shall have the right to have their parents or parent substitutes with them at all times.

Virtually all the wards have open visiting arrangements for parents. This is more restrictive for parent substitutes in adult wards in general or community hospitals.

All wards acknowledge parent substitutes, however, a quarter of the wards do not allow children or young people to have a say in who visits them. These wards tend to be adult wards in general or community hospitals.

24% of wards (specifically adult wards and neonatal wards or special care baby units) do not allow parents or carers to accompany children in the anaesthetic room and of these, 33% do not allow parents or carers in the recovery room.

9.2 Article 3: Accommodation should be offered to all parents and they should be helped and encouraged to stay. Parents should not need to incur additional costs or suffer loss of income. In order to share in the care of their child, parents should be kept informed about ward routine and their active participation encouraged.

Space restrictions mean that in some wards only one parent can stay. This affects high dependency unit (HDU) wards particularly. Hospitals have limited separate parental accommodation which means a heavy reliance on fold down beds at the bed side (over half of the wards participating in the survey). These wards cannot offer personal storage space for parents.

All hospitals which offer accommodation to parents were doing so free of charge. However, less than half of the wards offer food to parents at a subsidised rate. This means that parents in these wards are incurring additional costs. This is a particular issue in wards in children's hospitals. Children in these wards are often there for some considerable time resulting in considerable costs to the parents.

It is not clear if wards are providing assistance to parents in cases where financial circumstances prevent them from staying. Information on reimbursement of travel costs, for example, is not always obvious in wards and many of the parents interviewed are not aware of whether they are able to reclaim costs.

The majority of wards provide parents with information about the ward routines. However, this is problematic in some cases where the admission is an emergency. Wards tend to rely on this information being supplied with admission documentation. This only applies in planned admissions and in some cases staff do not make contingency arrangements for parents coming to the ward in an emergency.

9.3 Article 4: Children and parents shall have the right to be informed in a manner appropriate to age and understanding. Steps should be taken to mitigate physical and emotional stress.

The Charter states that services should:

- Provide information and programmes to prepare children and parents for a stay in hospital, whether planned or emergency
- Offer play and recreation activities suitable to the child's age and development
- Be aware that a child may become stressed by being isolated or as a reaction to the condition of other patients and take appropriate action.
- Feature stress free and appropriately equipped rooms allowing children and parents the opportunity to retreat.

Whilst wards provide information for parents/carers, the format and content of this varied considerably. Some wards provide written information which is sent out prior to admission and/or available in the ward or at bedsides, others provide verbal information at admission. Feedback from parents/carers suggests that, in some situations, notably in the case of emergency admission, the information is either not provided or not retained by the parent/carer.

Access to support services for parents is mixed and tends to focus on social work, with just over half of wards offering family support or family liaison workers. Indeed, one in five wards do not offer access to any of these support mechanisms.

Almost all wards offer parents/carers access to spiritual care and bereavement support, although the format of this varied.

Children nursed on adult wards, lack appropriate care in terms of paediatrically trained staff, the physical environment, access to play, recreation and education provision and programmes to prepare for a stay in hospital.

9.4 Article 5: Children and parents have the right to informed participation in all decisions involving their healthcare.

Three quarters of wards involve children and young people in decision making and encourage feedback and questions. Those that did not, tend to be adult wards or children's wards in general hospitals. However, the survey did not explore how this involvement is obtained or the suitability of the format or content of the information provided.

9.5 Article 6: Children shall be cared for together with children who have the same developmental needs and shall not be admitted to adult wards.

The children's wards in the general hospitals admit children up to the age of 16, thereafter young people are admitted to adult wards. However, a third of the wards surveyed are in children's hospitals which generally stop admitting children at a younger age (13 or 14) and so, beyond this age, children and young people are admitted to adult wards.

The results from the survey suggest that the recreational and infrastructural needs of children are being better served than those of young people. Few wards have adolescent units, placing them in beds close to younger children. Recreational opportunities were also much more limited for young people than for children.

Visiting arrangements for siblings and friends tend to be more restrictive than for parents and carers. However, these restrictions do not appear to relate to age but to the condition of the sick child and the health of the visitor.

9.6 Article 7: Children shall have full opportunity for play, recreation and education suited to their age and condition and shall be in an environment designed, furnished and staffed and equipped to meet their needs.

The opportunity for play appears to be dependent on the type of ward to which the child or young person is admitted. Availability of play opportunities is most restricted in adult wards. Since some wards do not admit children beyond the age of 13, these older children and young people will not receive the same opportunities for recreation as their peers admitted to a children's ward in a general hospital. On many adult wards they are lacking access to appropriately trained staff, to appropriate play provision, recreation and education, and to an environment that is equipped to meet their needs.

As previously stated, play opportunities tend to favour younger children rather than adolescents. Play opportunities for children with additional support needs varied considerably, being dependent on the type of ward and hospital. Opportunities are best for children with additional support needs in children's hospitals. Recreational opportunities for young people, including internet access, are generally poor and worst of all in adult wards.

None of the adult wards indicated that they provided access to teaching for children and young people and in the 22 children's wards that provided information about the interval between admission and a request for teaching being made, the norm was 7 days but was 5 days or less in 5 wards and more than 14 days in 1 ward. Eight (27%) of children's wards do not make provision for children from other local authority areas. This appears to be the result of a system in which the local authority where the child lives is required to pay the hospital based local authority for the provision of education by a hospital based teacher, but may prefer to provide a teacher itself. The downside of this cumbersome arrangement is that by the time the hospital has contacted the child's local authority and the local authority has responded, there is a good chance that the child will have been discharged.

9.7 Article 8: Children shall be cared for by staff whose training and skills enable them to respond to the physical, emotional and developmental needs of children and families.

Despite Scottish Government advice, there are still children below the age of 16 being cared for in adult wards across Scotland. In these cases, the service provision does not comply with the required standard.

10 Progress since the previous survey

This is ASCS's seventh survey looking at parental access and family facilities in Scottish hospitals. There have been some changes to the questionnaire since the last survey in 2005/07. However, where possible, comparisons have been made with the results from this survey to highlight areas where improvements have been made, areas which have remained the same and areas where there has been some reduction in service provision. Graphs highlighting areas of progress can be found in Appendix 6. The purpose of this review is to highlight areas on which ASCS and its partners should potentially focus in the future.

10.1 Areas of progress

The results from this survey suggest that improvements have been made in relation to:

- **The availability of information for parents on the reimbursement of travel costs which has increased from 83% to 88% of wards**
- **The availability of play specialists which has increased from 55% to 70% of wards**
- **The provision of vending machines has increased from 74% to 87% of wards**
- **Availability of family liaison/support worker which has increased from 38% to 55% of wards**
- **Compliance with Scottish Government guidance on education which has increased from 3% to 24% of wards**

10.2 Areas which have shown no change

The results from this survey suggest that the following areas have remained the same over the period between this and the last survey:

- **Allowing parents to remain in the recovery room**
- **Availability of parents' overnight accommodation at bedside**
- **Availability of dedicated play rooms**
- **Provision of open visiting for parents/carers**
- **Dedicated day surgery lists**

10.3 Reduction in provision

The results from this survey suggest that the following areas have experienced a reduction in provision:

- **The number of wards offering a choice of child or adult wards for young people reduced from 29% to 13%**
- **Use of a dedicated named nurse policy reduced from 84% to 70% of wards**
- **Allowing parents to remain with their child till they are anaesthetised reduced from 89% to 76% of wards**
- **Provision of open visiting for siblings reduced from 66% to 37% of wards**
- **Provision of self-catering facilities for parents/carers reduced from 38% to 13% of wards**
- **Provision of a dedicated day surgery ward reduced from 59% to 44% of wards**
- **The provision of cafe facilities accessible to parents/carers has decreased from 92% to 83% of wards**

It is recognised that some of the wording on questions has been changed since the 2005/07 survey which has prevented comparison between results. Furthermore, it is possible that, on occasion, the reconfiguration of a clinical service involving consolidation onto fewer sites may appear to reduce provision but actually represent a more effective service.

Despite some changes in service configuration and changes in the wording of some questions and the inclusion of new questions, a review of the responses to those questions which have remained unchanged between 2005/7 and 2012/13 demonstrates that, overall, progress in meeting the expectations of the EACH Charter has been mixed, with a reduction in provision in a number of areas. However, it is pleasing to see improvements in parent accommodation in hospitals as well as improvements in the availability of play staff.

11 Conclusions and recommendations

11.1 Conclusions

The results indicate that there has been some progress on aspects of parental access and family facilities since the previous 2005/07 survey, particularly in relation to availability of overnight accommodation, provision of play staff, provision of information relating to ward routines, and enabling parents to accompany their child to theatre before surgery. It is noteworthy that, in all the hospitals visited, the articles of the EACH Charter are prominently displayed. Data from the survey and feedback from parents and staff from visits to hospitals has also highlighted some areas which are either not meeting expected standards or are not meeting parental needs and expectations.

The areas of progress and outstanding issues are considered below.

11.1.1 Parental access

Wards appear to be flexible in their approach to visiting and offer virtually unrestricted access to parents whose children have been admitted. This is in line with article 2 of the EACH Charter. However, access appears to be more restricted for parent substitutes, with some wards allowing visiting only by agreement or at limited times.

Access is also more restricted for siblings, although this tends to relate to the health of both the patient and the sibling visitor. However, in some cases access is restricted for siblings due to lack of space around the hospital bed. Additionally, few of the wards appear to have creche facilities. These limitations mean that parents with other children would have to make arrangements for them to be cared for when they visit their child in hospital; separation from siblings may create emotional difficulties for the patient.

11.1.2 Parental facilities and accommodation

More than one in ten wards (13%) admitting children do not offer overnight accommodation to parents or parent substitutes. Less than half the wards which do offer accommodation made this information known in the pre-admission paperwork. Nevertheless, the survey suggests that improvements have been made in the availability of off-ward parental accommodation. This may be as a result of changes made to ward layouts and facilities arising from the construction of new hospitals since the previous survey (eg Dumfries and Galloway Royal Infirmary, the development of the children's unit at University Hospital Crosshouse, Forth Valley Royal Infirmary etc.).

The survey also highlights restrictions in space in some wards which limit opportunities for parents to stay or which restrict the option of overnight stays to one parent only and also limits opportunities for siblings to stay.

A key issue identified from the survey and raised by parents during the hospital visits is lack of laundry and kitchen facilities. Few wards provide self-catering facilities or washing machines. This means that parents incur additional costs when visiting their child in hospital (contrary to article 3 in the EACH Charter). Parents have to purchase meals instead of making their own and have to use local launderettes at extra cost.

Adult wards generally did not have sitting rooms which parents can use. Feedback from the discussions during the hospital visits suggest that parents like the opportunity of having a break from being with their child but do not want to be too far from them in case the child becomes stressed or a problem arises.

Many adult wards have no facilities for parents. This is a concern given that, in some health board areas, young people from the age of 12 are admitted to adult wards despite Scottish Government guidance (Better Health, Better Care: Hospital Services for Children and Young People in Scotland: 2009; http://www.scotland.gov.uk/Resource/Doc/271943/0081051.pdf) that children up to the age of 16 should be admitted to paediatric facilities. Feedback from parents suggests that they would still prefer to remain with their child in adult wards. Lack of parental facilities in the majority of these hospitals means that these parents are not offered the opportunity to take a break during their visit or to stay overnight with their child.

Family support appears to be focused on social work as opposed to other support services. Also, nearly half of neonatal wards or special care baby units did not operate a named nurse policy. These failures create a potential issue under article 4 of the EACH Charter.

Feedback during discussions with parents suggests that they are often unaware of the support available to them and/or of their financial entitlements. Therefore, whilst the survey suggests that wards make this information available, it may be that parents do not receive it or do not understand it. Access to a family support worker might help to address this.

Parents' access to refreshments is variable. There are few self-catering facilities in hospitals for parents, making the hospital canteen and vending machines the only options available for refreshments. Whilst the survey suggests that parents/carers can get access to drinks free of charge, the majority of wards are unable to provide free or even subsidised meals (contrary to article 3 of the EACH Charter).

Whilst some wards are able to provide parents with a discount voucher for use in the hospital canteen, many are not and in such instances parents have to pay full price for meals. Feedback from parents suggests that they found this very costly, particularly if their child is in hospital for more than a few days. It should also be noted that some hospitals can only provide one parent with a discount voucher.

Feedback from staff and parents during the hospital visits also suggests that wards are not able to allow parents to eat on the wards. Parents expressed concern at having to leave their child to go to the hospital canteen as, in many hospitals, it is some considerable distance from the ward. As a result, some parents rely on vending machines or even skip meals.

11.1.3 Young people's services

Wards appear to recognise the importance of engaging with young people and do involve them in discussions about their treatment etc., but there has been a substantial reduction in the number of wards giving young people a choice as to whether they should be admitted to a child or adult ward. Many of the ward facilities are more appropriate for children than for young people. Few wards have adolescent specific areas either for beds or for recreation. The recreation equipment is also limited for young people (contrary to articles 6 and 7 of the EACH Charter).

This issue will be addressed in some wards such as in Dumfries and Galloway and Glasgow, with the construction of new hospitals, but few other wards indicated an intention to upgrade their facilities for young people.

11.1.4 Ambulatory care, short stay and surgery

The survey suggests that there have been some improvements since 2005/07 in respect of parental opportunities to be on the ward with their child prior to surgery. However, there has been some reduction in opportunities for parents to be with their child whilst they are anaesthetised and opportunities to be with their child in the recovery room remain low at 67%. There is some variation in practice depending on ward type with adult wards, neonatal wards and special care baby units being least likely to allow parents to accompany children to surgery – indeed one in five did not allow this at all.

11.1.5 Records and feedback

The survey suggests that wards are engaging with parents/carers, children and young people to obtain their feedback on service provision and design. Feedback from the visits to the wards confirmed the use of ward surveys to gather feedback.

However, the survey did suggest that few wards facilitate parents/carers or young people's access to their records. The wards did appear to have procedures in place for parents/carers or young people to request access but these were often lengthy and therefore only appropriate for patients with longer lengths of stay. Feedback from parents during the ward visits suggests that they are not aware that they can access the records. This may indicate that either the information is not being made available to parents or that they do not understand the information provided.

11.1.6 Travel

The survey indicates a considerable increase in the number of wards making an effort to provide information available to parents on travel costs. However, feedback from parents during the ward visits suggests that they are not aware of their entitlement to travel cost reimbursement. Often this information is available in admission documentation and it may be that parents of children admitted in an emergency do not receive this information.

11.1.7 Education

It appears that none of the adult wards surveyed provides access to teaching for children and young people. Where any reason was given, it was that the admissions were too short to warrant such provision. However, brevity of stay seems unlikely to be relevant in all cases as admissions to orthopaedic wards, for example, are often protracted.

The recent data suggests that since the previous survey there has been some reduction in the delay in requesting education following admission. The overwhelming majority of wards (95%) appear to be able to request education provision after children have been in hospital for one week as opposed to two weeks previously reported. However, The Scottish Government Education Guidance for Children Absent from School Due to Ill Health (2001) states that hospital education should be provided after 5 days in hospital depending on the health of the child. Where it is known that a child is likely to be in hospital more than 5 days the guidance says that, depending on the child's health, education should begin immediately. Only 5 (24%) of children's wards comply with this guidance and those that do not are in contravention of Section 40 of the Standards in Scotland's Schools etc. Act 2000.

Whilst education is provided in all children's wards, it is impossible to gauge the adequacy of this provision since wards were unable to provide details on how much time is spent in education per day per child. Furthermore, the survey suggests a limited availability of dedicated classrooms as well as limited availability of additional support teachers.

Just over a quarter of wards reported that they do not provide education for children from other local authority areas (i.e. these children would not receive any educational input unless they were from the local authority in which the hospital is located). This may reflect differing arrangements between health boards and local authorities for payment for teaching support. Few wards have access to a teacher from the child's local school.

11.1.8 Play

The survey suggests there has been an increase in play staff since the previous survey. This is encouraging. However, feedback from play staff interviewed in the ward visits highlights difficulties in accessing training for play specialists. The course is no longer offered in Scotland and is not offered as an e-learning option, making it very difficult for play staff in Scottish hospitals to improve their skills and knowledge and seek promotion. Play staff are concerned that this may limit the number of trained staff in hospitals in the future.

Feedback from the hospital visits indicated a reduction in play staff hours in some wards but in the children's hospital in which this issue had been raised by staff, it transpired that the reduction in hours for some wards had been accompanied by an increase in hours for others in an attempt to provide an equitable distribution of play staff hours. The survey also highlights that some wards do not allow parents or children to use play rooms unsupervised. This, combined with the reduction in staffing hours, may restrict availability for play for some children.

Recreation facilities for young people are very limited. The survey highlights limitations in the availability of adolescent specific facilities and feedback from the ward visits also highlights limitations in recreational opportunities for young people. Access to the internet, so important for a young person's social interaction and play, is limited, with less than half the wards providing it. Many of the games etc. available on the wards are more suitable for younger children.

The survey also suggests that improvements may be needed in the provision of play preparation, distraction therapy and post procedural play, since the results indicate that not all babies, children and young people receive this consistently.

11.1.9 Child Health Commissioners

Only 7 out of 14 Child Health Commissioners (CHCs) responded to the second survey specifically addressed to them. Data from the CHCs was limited as respondents did not appear to have the required information readily available, and the information they held relating to admissions of young people was particularly limited. This is in spite of the fact that a key responsibility laid upon CHCs is to ensure that appropriate information systems are in place to ensure the provision and monitoring of child health services (National Template for Child Health Services, 2000).

The responses that were received were variable in content and format and not appropriate for analysis. The role of the CHC appears to lack clarity and consistency with health boards adopting different approaches to the role and the priority given to it. These issues, together with deficiencies in the recording of admission data, has impacted on the information available for this research.

11.2 Recommendations

The recommendations highlight issues which should be addressed to ensure further improvement in the provision of services for children and young people's in accordance with the EACH Charter.

11.2.1 Admissions

- Children and young people under the age of 16 should not be admitted to adult wards and those between 16 and 18 should be given the choice of ward type to which they are admitted.
- The Information Services Division should make information on the admission rates of 15-18 year olds available on its website.
- Adult wards should record the number of children and young people under 18 admitted.
- Consideration should be given to the needs of 16-18 year olds admitted to adult wards.
- Adolescents should be cared for with others of a similar age.

11.2.2 Parental access and facilities

- All wards admitting children and young people should offer to parent/carers and parent substitutes the following:
  - Overnight accommodation and unrestricted visiting
  - A sitting room close to the ward with self-catering facilities
  - Subsidised meals in the hospital café /staff cafeteria
  - Laundry facilities for the parent/carers of long stay patients
  - Washing and showering facilities.

11.2.3 Information

- Ward staff should ensure that the following information is understood by patients and carers (not just made available), both for elective and emergency admissions:
  - Arrangements for overnight accommodation for parent/carers
  - Availability of family support, including help with travel expenses
  - The named nurse
  - Accommodation, facilities and access for carers.
- There should be:
  - Healthy menus specifically designed for children and young people
  - Information regarding the nutritional value of meals, possibly using a 'traffic lights' system to guide healthy choices
  - Age appropriate tableware.

11.2.4 Surgery

- Surgery should be provided on dedicated lists with identified anaesthetists allocated to children's surgery.
- All children should have the right to have their parents/carers stay with them until anaesthetised prior to surgery, and to be present in the recovery room after surgery.

11.2.5 Education and Play

- All children and young people, whether admitted to children's wards or adult wards, should have access to:
  - Education provision no longer than five days after admission, irrespective of the location of the hospital relative to the local authority area where the child normally resides (assuming the child's health makes this appropriate).
  - Provision of education immediately if it is known on admission that the child will be in hospital for longer than five days.
  - Qualified play staff and recreational facilities appropriate to age and development.

11.2.6 The role of the Child Health Commissioner

The health of its children determines the future health of the Scottish population and the effectiveness of each health board's Child Health Commissioner is crucial. To be effective:

- There needs to be clarity about the role of the Child Health Commissioner and consistency across health boards. To this end, the CHC must:
  - Have a clear job description
  - Take the lead in the development of the Child Health Strategy, planning and commissioning child health services
  - Have appropriate information systems in place to ensure the provision and monitoring of child health services.

National Template for Child Health Services: http://www.sehd.scot.nhs.uk/cyphsg/Documents/A%20Template%20for%20Child%20Health%20Services.pdf

Action for Sick Children Scotland (ASCS) is the only Scottish charity which promotes the needs of ALL sick children and young people within our healthcare system. We work for improved standards and quality of care for children and young people when they are ill in hospital, at home or in the community. We aim to represent their needs and those of their families and ensure that their voices influence health policy, planning and practice. We do this in partnership with parents, carers, professionals and children and young people themselves.

➜ **Our Vision** is for the best quality healthcare for children and young people in Scotland.

➜ **Our Mission** is to enable children and young people to meet their individual healthcare needs, in partnership with parents, carers and professionals.

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