

**PE1471/B**

3 April 2013

Mr Andrew Howlett  
Assistant Clerk to the Public Petitions Committee  
T3.40  
Scottish Parliament  
EDINBURGH EH99 1SP

Dear Mr Howlett

PETITION PE1471

Action for Sick Children Scotland (ASCS) is pleased to have been invited to respond to the petition submitted by MSYP Rachael McCully. ASCS works for improved standards of health care for children and young people and promotes their health needs and rights at times of illness. ASCS is a member of the European Association for the Welfare of Children in Hospital (EACH) and our work is underpinned by the principles of the EACH Charter<sup>1</sup> – the ten rights of children and young people in health services – and their corresponding rights as set out in the UNCRC. Our work has the wellbeing of children and young people as its central focus.

We welcome this petition and commend the Petitioner for raising very pertinent issues around the need for age appropriate facilities for young people in hospital. We are sure that many young people who have been treated in hospital and those working in hospitals will recognise the issues raised. ASCS's comments on what the petition seeks and the discussions that took place are as follows:

The Scottish Government's 'National Delivery Plan for Children and Young People's Specialist Services' (2009) and 'Better Health, Better Care: Hospital Services for Young People' (2009) state that children up to the age of 16 should be catered for in children's hospital services and that this should be accompanied by specific planning and investment to ensure young people receive age appropriate care. This has not yet been implemented.

In the larger paediatric hospitals, children up to the age of 13 are admitted. However new admissions over the age of 13 years are sent to adult hospitals. Children over the age of 13 years who are receiving ongoing treatment at Children's hospitals eg those with long term chronic conditions are given the choice of staying in the children's ward or moving to an adult hospital. Practice varies in other hospitals which are not dedicated sick children's hospitals; some may admit children up to the age of 16 years to their paediatric services.

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<sup>1</sup> The EACH Charter: <http://www.ascscotland.org.uk/default.asp?page=66>

Facilities in existing dedicated Sick Children's hospitals were not designed for older children and young people so the new sick children's hospitals planned for Edinburgh and Glasgow provide an opportunity to provide age specific facilities. We understand that single rooms will be available in these new hospitals for children and young people regardless of age. It will therefore be important for young people to have opportunities for socialising, access to media etc such as the adolescent lounge area planned for the new hospital in Glasgow.

One contributory factor for the lack of young people's wards in general hospitals is that care is generally delivered on the basis of clinical speciality rather than age. This means that few young people are in hospital at the same time within each speciality. Many consultants, particularly but not exclusively those from adult services, prefer to have their patients in one location rather than scattered throughout the hospital and are concerned that nursing care for their speciality should be provided by nurses with experience in that speciality. It requires a shift in attitude to move from this current position.

Evidence from adolescent wards in England and abroad suggests that young people's wards work very well and that regular rotation of staff between wards and upskilling of staff through appropriate staff training have resolved any such concerns. The attitude of Healthcare Professionals has been known to change where services for young people have been put in place and antipathy has turned into demand for this service. Research such as 'Youth Matters: Evidence Based Best Practice for the Care of Young People in Hospital: Viner R and Keene M, (1999)' shows the significant benefits for young people in hospital of being able to interact with others of their same age or stage in an age appropriate environment.

ASCS is of the view that dedicated young people's wards are the most appropriate for many young people but if these cannot be implemented, adolescent friendly zones must be available. In the meantime improvements for young people could be considered, such as unrestricted visiting for friends and families of young people in hospital; appointment of specialist nurses for young people in each Board area.

The need for staff working with children and young people to be trained to work with children and young people is absolutely critical. The emotional and physical needs of children change as they become young people and both children and young people have different emotional and physical needs from adults. Paediatric staff training does not cover the needs of young people so staff in both paediatric and adult wards should receive training to support them to work with young people. ASCS is very concerned about the falling numbers of paediatrically trained staff in Scottish hospitals treating children.

The petition refers to the Scottish Government's commitment in 'Better Health, Better Care: Hospital Services for Young People (2009)' to require all NHS Boards to ensure that all staff routinely working with young people are trained to work with this age group by 2013. NHS Education Scotland has developed a multi disciplinary e-

learning education<sup>2</sup> package for health care staff working with adolescents. We are unsure what the uptake has been for this essential training resource.

'Think Transition: Developing the essential link between paediatric and adult care: RCPE: (2008)' reports on the need for smooth transition from paediatric to adult services for children and young people with long term conditions. While paediatricians support and recognise the need for smooth transition to adult services for young patients, this needs to be equally recognised in adult services. During adolescence, children with long term conditions often take risks such as stopping medication or failing to turn up for medical appointments. This risk taking behaviour can have serious impacts on their health so it is even more important that age appropriate support is provided to young people before, during and after transfer to adult services.

It is critical that children, young people and their families are involved in hospital service planning and design so that planners and providers can be informed about their needs and concerns and that these can be met. All Health Boards are aware of the need to engage with children and young people in the planning of their children's services and there are examples of good practice.

We note the reference to the Teenage Cancer Trust Units and the gold standard of care provided for young cancer patients. ASCS feels that this same high standard should be provided to all young people in hospital irrespective of their condition.

The Petition and proceedings vividly describe the feelings/experiences of some young people who have been treated in adult wards or in children's ward with much younger children. This chimes with what children, young people and families tell us. The following are some examples:

- a 14 year old boy terrified because he was placed in an adult men's ward next to a dying patient;
- a 14 year old 'looked after child' placed in an adult ward who overheard cancer patients talking about how long they had to live. As this was before her own condition had been diagnosed she thought that she also had cancer and that she was going to die;
- 13 year olds turned away from Accident & Emergency Departments at dedicated sick children's hospitals;
- a 14 year old girl attending Accident and Emergency with symptoms of acute appendicitis, who was distressed at seeing a semi-naked drunk man and another patient being resuscitated in a nearby bed;

Placing children and young people in adult wards can raise child protection issues because of placing children and adults patients together in the same environment. Health Boards will also be aware of the need to ensure that staff caring for children in adult wards are PVG scheme members, regulated to work with children.

The Petitioner raises the very important issue of the right to education for children and young people when absent from school due to illness. She points out that children and young people placed in adult wards do not receive access to hospital

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<sup>2</sup> <http://www.knowledge.scot.nhs.uk/child-services/communities-of-practice/adolescent-health-care.aspx>

tuition which is available in children's hospitals. This issue is one of which the Scottish Government Stakeholder Group reviewing the Guidance on Education for Children Absent from School due to Ill-health is aware. ASCS is a member of this Group and hopes that the education rights at times of illness of all children and young people, including those in adult hospitals, will be met.

We agree with the Petitioner when she says that it is the right of every child and young person in hospital to receive the best possible care; that children and young people have the right to express their views and that these should be listened to; that they should have the right to recreation and education in hospital; that they should be treated by those trained to work with them. All of these rights are healthcare rights outlined in the EACH Charter.

In conclusion ASCS is delighted that Racheal McCully and the Scottish Youth Parliament has brought forward these very important issues to the attention of the Scottish Parliament Public Petitions Committee and we support this petition.

Yours sincerely

Elizabeth May  
National Co-ordinator