

Consultation response from Action for Sick Children Scotland on moving the Children's Ward 15 from the Royal Alexandra Hospital to the Royal Hospital for Children Glasgow.

This response is on behalf of Action for Sick Children Scotland (ASCS) an organisation which has for more than thirty years campaigned for children and young people to receive the highest standard and quality of care when they are ill in hospital, at home or in the community. Whilst our core purpose remains that of influencing and collaborating to secure best health care outcomes for sick children and young people, our activities also reflect the dynamic developments in the planning and delivery of health care in Scotland today. We work in partnership with parents, carers, health care professionals and most importantly with children and young people themselves. Our vision is for the best quality healthcare for children and young people in Scotland.

ASCS is a member of the European Association for Children in Hospital (EACH). A key focus for members is the EACH Charter and its ten Articles which explain the rights of children, young people and families when using health care services. The EACH Charter is underpinned by the United Nations Convention on the Rights of the Child (UNCRC) and members aim to have the principles of the EACH Charter incorporated into their countries' health laws, regulations and guidelines. A rights based approach has strongly informed our response to the current consultation.

Our Involvement in the Consultation to date: Dagmar Kerr, as a parent and Action for Sick Children Scotland Area Coordinator for NHS GG&C, has been a member of the Ward 15 Stakeholder Reference Group. She and Action for Sick Children Scotland Executive Committee member, Gwen Garner, have also attended public meetings and spoken to families who will be affected by the move. They were also involved in the consultation process in 2011.

The UNCRC and the EACH Charter

Our response to the consultation is set in the context of the United Nations Convention on the Rights of the Child (UNCRC) ratified in 1991 by the UK, and the European Association for Children in Hospital (EACH) Charter. The latter recognises and endorses the rights of the child as stipulated in the UNCRC, and in particular the key principle that, in all situations, the best interests of the child should prevail (art.3).

The EACH Charter relates to the UNCRC General Comment No 15 (2013) on the child's right to the enjoyment of the highest attainable standard of health (art. 24), and to the UNCRC General Comment No. 4 (2003) on adolescent health and development.

The Scottish Government recommends that NHS Boards review their provision of children's hospital services with reference to the EACH Charter and put in place plans to address any issues identified. (Delivering a Healthy Future: An Action Framework for Children and Young

People's Health in Scotland (2007). We have therefore looked at the proposal to move Ward 15 to the Royal Hospital for Children (RHC) in the light of the 10 Articles of the Charter.

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.

Children are admitted less often as inpatients than a few years ago and therefore the demand on bed numbers has fallen significantly. As a result, Ward 15 has on average 8 patients a day. We understand that the RHC has on average 30 – 40 free beds and therefore sufficient capacity to accommodate children and young people from Ward 15.

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

This right is possible and encouraged on both sites.

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

Parents can stay with their children in Ward 15 in chairs or beds beside their child's bed. In the RHC, parents have built-in beds and 80% of children will be treated in private rooms and en-suite facilities. The parent accommodation at the RHC is more comfortable.

However, for families who live close to the RAH, the move to the RHC will mean a longer distance to travel and time away from home and this might make visiting or staying with their child more difficult. For some families the changed location will make no difference, while others might have a slightly shorter journey.

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

NHS GG&C supports age appropriate care and it should make no difference where this care is delivered. However, the RHC has a dedicated service for young people over the age of 12 and is therefore in a position to offer more specialised support to that age group.

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

As above - the dedicated youth service at the RHC allows for more age appropriate support for young people.

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

Under the proposal, seriously ill children will receive more specialised care more quickly, as they will be taken to the RHC immediately. At present they would be seen at the Royal Alexandra Hospital first and then would have to be moved again, if they needed more specialised care.

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

Both hospitals offer a dedicated paediatric service where children are cared for in children's wards. The RHC can however offer more choice and more specialised support for different age groups through their play service, youth service and volunteer programme.

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.

The RHC hosts a hospital education service (HES), a play service and a youth service. There is no teaching service for the children and young people who are being treated at Ward 15. In the RHC, the hospital teachers visit the wards every day to identify the patients who would benefit from and qualify for teaching. The play, youth and activities programmes at the RHC give patients of all ages the opportunity for play and recreation. Ward 15 also has some play staff.

More specialist imaging and treatment equipment is available at the RHC, and it is a more disability friendly environment. Some rooms at the RHC have built-in hoists and there are excellent changing facilities for disabled children, young people and adults. However, there are some issues around automatic doors that still need to be addressed.

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.

There is no doubt that all staff in Ward 15 and at the RHC are trained and skilled appropriately. However, members of the NHS GG&C Health Board make a compelling case that the Board is not able to meet all national clinical standards set by the Royal College of Paediatrics and Child Health (RCPCH) at Ward 15. Action for Sick Children Scotland supports these clinical standards and campaigns for children and young people to have access to the best available clinical care. Action for Sick Children Scotland also supports the need for excellent training for junior doctors such as the training available in the RHC.

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

Parents and carers of children and young people at Ward 15 have expressed how much they value the fact that staff know their child and that they have an "open access" policy. In the case of the ward moving to the RHC, these parents need to be supported and reassured that their child will still receive very personal and individual care and that the links with the PANDA centre and community nursing will be strong and consistent. If the proposal goes ahead, a similar "open door" policy needs to be agreed with families whose children's needs require this.

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

All staff in NHS GG&C aim to treat patients with tact, respect and understanding. The new hospital offers excellent facilities, especially single rooms and en-suite bathrooms that will give children and young people and their families extra privacy. Consultation with young people shows that they very much value this.

Conclusion

Action for Sick Children Scotland is of the view that the Health Board has made every effort to consult with families who are affected by this proposed change. However we understand how hard it must be for families to feel that they are losing a valued service. The impact on those who currently live very close to the Royal Alexandra Hospital should not be underestimated. They will face longer travelling times and will find it more difficult to manage home commitments as well as supporting a child in hospital. At the same time there are many families within NHS GG&C who have always had longer and more difficult journeys.

The most compelling argument, however, is that clinical standards are there to support the best quality healthcare for all children in Scotland and we feel that this would achieved by moving Ward 15 to the RHC. This is underpinned by article 24 of the UNCRC.

Recommendations

- Action for Sick Children Scotland recommends that community nursing services are strengthened in the Board area so that more children and young people can be supported through them, the PANDA Centre, and the out-patient clinics remaining at the RAH.
- The Board and RHC should ensure that family support and information services are appropriately resourced and that all staff are able to signpost families to appropriate information and services. Every effort needs to be made to inform parents about support services, like income maximisation, travel cost support and emotional support to help.
- "Open door" policies should be available for patients and their families who would benefit from those.
- Families should be kept informed about progress and get plenty of notice, if and when changes are going to happen.
- Families are worried about ambulance services. Action for Sick Children Scotland recommend that the Board put in place a strategy to ensure families are well informed about how a move to the RHC will be supported and how the Scottish Ambulance Service will adjust to such a move if it goes ahead.
- The Board should ensure that information at each stage of the process should be available to all stakeholders.

Dagmar Kerr Area Coordinator for Greater Glasgow and Clyde c/o Action for Sick Children Scotland 22 Laurie Street Edinburgh EH6 7AB

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