

PE1471/M

Mr. Chris Hynd
Assistant Clerk to the Public Petitions Committee
The Scottish Parliament
Edinburgh
EH99 1SP



3rd May 2013

Dear Mr. Hynd,

Re: Responses to Public Petition PE1471

I welcome the opportunity to comment on the responses to my petition. I'm delighted by the support it has received from the wide range of organisations that responded, including NHS Boards, bodies representing medical professionals and charities alike.

I take great heart from the positive reaction towards my suggestions of dedicated young people's wards and improved training for staff involved in the treatment of young people in hospital. In particular, there is a clear recognition amongst all the organisations that young people have distinctive needs from children and adults, particularly when it comes to accommodation and facilities. The examples provided by the British Medical Association Scotland and Action for Sick Children Scotland, are similar to stories I have heard reported from young people who have undergone hospital stays. These examples should not be acceptable, show why my petition is necessary, and should be addressed through dedicated facilities for young people.

I am pleased some consideration and planning has been given to these issues by NHS Boards, although I am cautious about whether this consideration extends to young people above the age of 18. In detailing their provision for adolescents for instance, NHS Grampian comments that whilst the Royal Aberdeen Children's Hospital was "*built with adolescent care delivery in mind*" but "*there is no intention at this time to deliver care up to 21 for all young people*". References to work undertaken in responses from NHS Education for Scotland, NHS Ayrshire and Arran, NHS Greater Glasgow and Clyde also refer to 'adolescent' provision which makes me cautious that in these instances the organisations refer to in fact only offer provision for young people up to the age of 18.

My strong belief is provision for young people should at least extend to those up to the age of 21. As I referred to in my oral evidence to the Committee on 1st March, young people's wards should be for young people aged 16 to 25 ideally, 16 to 21 at least, as you are still developing as a young adult past the age of 18 and face similar problems with hospital provision. Whilst I agree with the point made by NHS Highland that in an ideal world "*perhaps transition to adult services should be person specific and not age related, considering maturity, although this may be difficult to implement*", in my experience of discussing this issue with a large number of young people who have been treated in hospital, young people's wards

for patients aged 16 to at least 21 would be the most appropriate range for the facilities. This age group shares many common characteristics central to my petition - the need for social interaction, the need for stimulating educational and leisure activities and a need to be treated with an age-appropriate level of respect and emotional support. Clarity on this point would be welcome, along with a recognition that the need for distinctive care for young people extends beyond the age of 18.

The policy of the Scottish Government to move away from wards to single rooms in new-build hospitals was raised at the Committee meeting on 1st March as a barrier towards the creation of young people's wards. I am pleased that Action for Sick Children Scotland, NHS Greater Glasgow and Clyde and the Royal College of Psychiatrists Paediatric Liaison Network raised this issue in their responses and I agree with their reasons setting out why this is not insurmountable, and am concerned that this policy has been designed without taking into account the views of young people.

Young people have clearly demonstrated that this is their preference when they have been given the opportunity to voice their opinion, as has been highlighted by NHS Grampian, NHS Greater Glasgow and Clyde as well as in SYP's and my own consultation work; and as the Liaison Network point out *"the social nature of adolescents outweighs the adult concerns regarding privacy, lending weight to the argument that adolescents need to be considered differently to adults."*

In their response, Action for Sick Children Scotland and NHS Highland propose sensible alternatives, should a single room-only policy being pursued. Dedicated and age-appropriate social spaces for young people in hospital should exist as a bare minimum. As I have raised in my earlier evidence, and as ASCS point out, the care provided in the Teenage Cancer Trust Units at the Beatson West of Scotland Cancer Centre, the Royal Hospital for Sick Children at Yorkhill, and the forthcoming units at the Western General and New Children's Hospitals in Edinburgh is indeed a 'gold standard' for the level of care provided to young people in hospital. I would urge decision-makers to carefully consider how the TCT example can be rolled out to young patients in hospitals in different parts of the country and with other conditions.

In a similar vein, I am also pleased that NHS Greater Glasgow and Clyde, the Royal College of Psychiatrists Paediatric Liaison Network and ASCS all raised the issue of how sub-specialist care can be provided in young people's wards and provide a compelling case to suggest why this issue, which was also raised at the Committee meeting on 1st March, is far from an insurmountable barrier to the creation of young people's wards. As the Liaison Network point out, *"few sub-specialties have their own wards in paediatrics except for the largest Children's Hospitals so the concern about subdividing each small ward to enable an adolescent area is not relevant for most hospitals...University College Hospital London has a dedicated adolescent ward that operates successfully across sub-specialties."* I would agree with the point made by ASCS that rather than practical difficulties, *"it requires a shift in attitude [from consultants and staff] to move from this current position"* and strongly believe that this change in approach is necessary and would be worthwhile.

The response from NHS Lothian presents an interesting example of consideration being given to separate facilities for young people. Whilst clearly having recognised that placing young people in adults wards is inappropriate, their proposed solution - moving young people from adult wards into private single rooms - does not address all the issues identified, and I would not recommend it being pursued more widely as it only focuses on the issues of child protection and distress caused to young people by elderly patients, and does not deal with the problems of isolation and loneliness facing young people in hospital.

I also note, from the Annex to NHS Lothian's response that "*after considerable review and discussion with our staff and young service users and their parents the new [children's] hospital will not include a dedicated adolescent ward for other specialties*". This is an extremely disappointing decision, and I would be interested to know further detail of what factors were considered in taking it, especially given that, as has been made clear to me by the young people I represent, and in the evidence from NHS Grampian, NHS Greater Glasgow and Clyde, ASCS and the RCPsych Paediatric Liaison Network, that single rooms are not considered to be the best option by young people.

I would urge NHS Lothian to reconsider this decision and would strongly encourage others planning new facilities to incorporate specific young people's wards into their planning. It is not too late to include specific, age-appropriate facilities into the design of new hospitals, such as the forthcoming new children's hospitals in Edinburgh and Glasgow, the New South Glasgow Hospital and other new-build facilities. I believe that this is not only necessary, but an excellent example of preventative spending.

Turning to the issue of appropriate training being given to staff involved in giving care to young people, I was again delighted by the level of recognition of the issue in the responses and by the support my petition received. The importance of training is noted in several responses and I also note the feeling amongst a number of the organisations that current provision and practice could clearly be enhanced, such as NHS Ayrshire and Arran and NHS Greater Glasgow and Clyde's comments that more specialist training on these issues would be useful and welcome; the examples of good practice provided from elsewhere by the RCPsych Paediatric Liaison Network; and the particularly strong views expressed by NHS Highland that "*the workforce needs to be equipped with the skills and competence to look after young people across the board. Current mental health services available to young people need to be redesigned.*"

This criticism of current mental health provision chimes with the experiences of young people who I have spoken to, who have been treated for serious conditions and simply been prescribed anti-depressants to cope with their emotional needs, rather than given quality mental health care. As well as a clear lack of appropriate mental health training, I feel this also reflects a lack of understanding about young people's rights in practice from staff. It relates to a point I made in my original submission that there is a clear issue with young people not being involved in decision-making about their own treatment which is reflective of problem which many young people have encountered - staff are uncertain whether to treat young

people as children or as adults, when in reality we are a distinct group with specific needs. I recognise that mental health services have improved and continue to do so, but can still very much depend where you are and who you are being treated by.

Given this, I am very encouraged to hear about the forthcoming training from NHS Education for practitioners working with children and young people, particularly in relation to consent decision making and the rights of children and young people. This training has the potential to make improvements to the care young people receive and the ability of staff to understand their needs and rights. I am also encouraged at NHS Education's willingness to develop further training on young people's transition and hospital care, and would strongly recommend decision-makers take them up on their offer, as I feel this would be very helpful in making the care young people receive appropriate to their age and maturity. I would also recommend that training is mandatory for all staff involved in the care of young people, rather than optional.

Whilst not an issue directly raised in my petition, the issue of appropriate Accident and Emergency provision was raised at the Committee meeting on 1st March and in the responses from Action for Sick Children Scotland and NHS Lothian. These examples are also very similar to experiences I have heard from young people who have required A&E treatment. In reality, the care young people receive in Accident and Emergency often appears to be dependent on the availability of paediatric staff on duty. In at least one A&E department, paediatric staff will treat young people up to the age of 21, which they have reported as very positive. This does however seem to be as a result of practice rather than policy, may be confined to one particular hospital, and is very dependent on the availability of paediatric staff at all times. Ensuring that appropriate mandatory training, as outlined above, is extended to all staff dealing with young people in Accident and Emergency departments may help address the unacceptable examples raised in the responses.

An extremely important point is raised in the response of the Royal College of Psychiatrists Paediatric Liaison Network, where in reference to potential financial and resource implications they refer to *"the potential life long health benefits have the potential to create large cost savings over the life span if young people/adolescents are given the best possible care at an early stage"*. An example of this is mentioned in ASCS's response, where they comment that *"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."*

This goes to the heart of why ensuring age-appropriate facilities and training for staff is so important. Ensuring that young people receive age-appropriate treatment is an investment that could make a significant improvement to the length of time they require care or the amount of time and money that needs to be spent on their care in the long-term. I feel that this is an example of where investment is required as preventative spend, and feel that this makes a very

compelling case for decision-makers to consider seriously the actions I have proposed in my petition.

Yours sincerely,

Rachael McCully MSYP