

Response to Children and Young People in Lothian Consultation

I welcome the publication of the draft Children and Young People's Health and Health Services Strategy for Lothian. I also found the presentation and workshops which I attended at Napier University to be useful and informative.

The comments I will make in this response echo some of the points I made in the workshop I attended.

- 1. The importance of listening to Children and Young People** – I think it's paramount that the Board listen to young people themselves when they are planning, reviewing and providing services. I noted particularly some of the young people quoted felt that staff spoke to their parents rather than to them. While this may be acceptable for a five year old it's clearly not acceptable for a fifteen year old.
- 2. The need to focus on Health Improvement** – A great deal of work has been done in schools to improve healthy eating. However, I remain concerned that decisions taken by the City of Edinburgh Council regarding, for example, the selling off of playing fields, can be made without any input from public health professionals. I welcome the fact that the Scottish Executive has recently announced more funding for school sports facilities but I would like to see NHS Lothian taking a more pro-active role in the promotion of sport and exercise with key partners. Recent statistics about the number of obese children and the knowledge we have of the long term effects mean that this is a key issue for the future.
- 3. Work should continue to be focussed in and outside school at the issue of addiction – smoking; drugs and alcohol.**
There should be targeted programmes in the most deprived areas as there is considerable evidence that young people there are more likely to start, to start earlier and to sustain such behaviour to the detriment of their health.
- 4. The need to Invest in areas of Need**
As the draft strategy says, Lothian is relatively affluent, however "the disparity in health between the most affluent and the least affluent is striking." Those on low incomes are less likely to enjoy good health and tackling this requires a joint approach from the NHS, the local councils and other parties including local communities. There is a need for good information as well as other services.
- 5. Young Carers, LGBT patients and other hidden groups**
Estimates suggest that there are up to 5,000 young carers in Edinburgh. It's essential that NHS Lothian works with schools and the voluntary sector to support these young people. This means that they must be able to get not only assessments of their own needs as carers but to have these needs met.

It's also essential that NHS Lothian takes on board the needs of the full range of communities in Lothian, including the needs of young LGBT patients and those from particular cultural or religious backgrounds.

6. Accessibility

There is a need to increase and improve the range of community services available to children and young people in exactly the same way that adults should be treated in local health centres and through out patient clinics wherever possible.

Young people have particular needs in terms of accessibility of services. Teenagers wanting to access sexual health services and clinics will want to attend these on their own and may experience difficulty getting time out from school. It might be sensible to have special appointment times out of school hours and at weekends so they can attend and to allow longer appointment times for younger patients of these services so that professionals and highly trained volunteers can give them information about safe sex, consequences of their actions etc.

7. Sick Children's Hospital

Like many other parents in Edinburgh I have cause to be grateful for the care my children have received at the Sick Kids over the years both as inpatients and outpatients. The Sick Kids has a particular place in the hearts of the people of this city and over the years they have shown that affection, respect and gratitude through the financial support they have given to the Hospital through various appeals that have raised millions of pounds.

However, I support the Board's decision to move from the existing buildings to a new site at Little France. The excellent care given by staff at the Sick Kids has often, in recent years, been delivered despite the buildings rather than because of them. Most of the buildings are old and overcrowded and access is difficult, particularly for patients and parents travelling by car.

I accept wholeheartedly that there is a clinical case for the Sick Kids being co-located with the RIE, in terms of access to diagnostic services and labs; quick transfer from the A+E department: strong relationships between specialist surgical services and the need for closer links with the neonatal service at Simpsons's Maternity Unit. I note that following the Bristol Enquiry the required standard for specialist children's services is for them to be located beside maternity, neo-natal and adult clinical services.

I would support a move to a new, purpose-built hospital next to the site of the RIE if these clinical needs are addressed and improved as a result of the move and with the following caveats;

- a) Given the financial support given to the Sick Kids in the past **I do not believe the people of Lothian would support this new children's hospital being built by the PPP method.** The neighbouring RIE has suffered from a lack of flexibility due to the contract based approach inherent in PPP. It has also had problems, as a result, in relation to car parking charges and meals that would both be totally unacceptable in a children's hospital. I would prefer not to see the new hospital built under a PPP scheme.
- b) Patients at the RIE have also had problems in relation to car parking charges and meals that would both be totally unacceptable in a children's hospital. **It's essential that parents and families coming to visit children in hospital, having to stay for prolonged periods of time and often having to travel significant distances given the regional remit of the RHSCE should not have to pay parking charges.**
- c) That there is a **review of the provision of public transport to the site**, well in advance of the move.
- d) That there is **improved provision for teenagers within the new hospital.** I welcome the Scottish Executive's view that patients up till the age of 16 should be in a ward designated for children and young people not an adult ward. However, there is a need to make sure that teenagers have their own space while they are in hospital where they can enjoy DVDs, games consoles and time away from adults.
- e) I would also like to see the **on-site provision of residential accommodation for parents** and family members who are having to stay with their children.
- f) I was the Convenor of the Health and Community Care Committee in the first Parliament when we passed the new Mental Health Legislation. Having visited mental health facilities including the Orchard Clinic and the Young People's Unit at that time I am committed to young people accessing appropriate services. I would wish to see the **Child and Adolescent Mental Health Services for young people, up to the age of 18, being co-located and expanded as part of this new build.** This would make sure that young people would be treated in accommodation which is appropriate to their needs and is close to family support. Too often, young people have had to be treated in adult wards or have had to travel to other Scottish cities to get inpatient care. While I agree that there is a need for an increase in inpatient places, inpatient care should be seen as a last resort and I would urge the Board to continue moves to improve intensive community outreach and 24-hour community services. I very much welcome the provision of the new Mother and Baby unit which was another

recommendation from our committee. I would echo the draft strategy's points on early intervention and transitional arrangements.

8. I am supportive of the Board's continuing work in **Child Protection**. There remains a critical need for good links between a number of services.
9. I am supportive of NHS Lothian's continued and expanded provision of **tertiary services**, including the Paediatric Intensive Care Unit.
10. In terms of **Children with Disabilities and Long Term Conditions** I would agree with much of the draft strategy. However, I would stress the need for good communication between agencies, the benefits of early intervention by specialist community services and would like the Board to consider the development of Child Development Centres across Lothian to allow better multi-agency assessment and intervention as a priority.

I appreciate the health commitment to respite support provision and would like to see this extended to assist families who are living with the consequences of a having a child with special needs. I would also be interested in seeing movement towards a single shared assessment and multi-agency recording systems.

I have had a number of parents who have come to me over the years, with concerns about points of transition for their children and the impact change has had both physically and mentally on their child. I have previously raised concern about the diminution of service provision when children move to adult wheelchair services. While I note that this is acknowledged in the draft strategy, I don't think the importance of getting transition right can be over-emphasised.

I do have concerns about the impact of Agenda for Change on recruitment and retention of SLTs, physiotherapists and some nursing groups, e.g community nurses. These are all key groups involved in early intervention and continued support of disabled children. I am also concerned at the lack of vacancies for newly qualified physiotherapists.

I also remain concerned that due to funding constraints Social Work are often unable to supply aids, adaptations and support services identified by health professionals as being necessary. Given the health professionals' duty of care it's essential that such shortfalls and difficulties are flagged up to the local authorities in a co-ordinated and systematic manner both in relation to the individual as well as collectively and cumulatively to the community as a whole.

11. The Board should keep children and young people's access to and use of **Dental services under review** and take any action necessary as a result.