



children's heart
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The Children's Heart Federation response to consultation on *Draft service specification standards for children's heart surgery services*

You will have already received comments from several of CHF Member Groups including Tiny Tickers, HeartLine, ECHO and Little Heart Matters and so we will not repeat the detail of their comments.

Most parents welcome the development of the standards, and the opportunity to be involved in their development. **Parents strongly support the proposed changes**, with more than seven in ten respondents to CHF's Ipsos MORI survey agreeing with the changes (73%) and almost as high a number (65%) agreeing that there is a **need for the changes**.

As far as the draft standards were concerned, and recognising that they are written for clinicians, parents feel that the standards need to:

- Be written from the perspective of the heart-child and in language that is accessible to parents/carers;
- Extend beyond specialist units to apply to services provided at local District General Hospitals.

Many parents also feel that they need further information before commenting on the actual standards:

Not clear how many centres there would be, not clear what effect this would have on waiting times, not clear what arrangements and support would be made available to families travelling long distances including financial support. Not sure what the evidence is regarding outcomes- for some more routine types of heart surgery this could still be done at more centres, with very specialised surgery being done at fewer centres for example.

We recognise that these issues will be addressed at the formal consultation stage; nevertheless, parents feel they need more information on how the service will be delivered in the future - particularly:

- How many surgical centres will remain and where these centres will be;
- Reassurance that this is not a cost cutting initiative;
- Greater explanation as to how the draft standards will be implemented (e.g. beds, waiting times);
- How will the proposed standards result in a positive impact on treatment;

- Will families receive better support than they currently receive (in terms of financial help with travelling and parental accommodation);
- What services will be provided locally - more detailed explanation of the hub and spoke service provision model.

There is a vocal minority who, because they live close to the surgical unit where their child has been treated and are concerned that that unit will close, do not support the changes. As they, too, have already given their views on the standards, I will not repeat the detail of their response. It is important that these views are heard and considered, and it is also important that they are not given inappropriate weighting.

Cecilia Yardley
External Affairs Manager

Childrens Heart Federation
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