

A Response to: Consultation On The Future
Commissioning Of Paediatric Cardiac Surgery &
Interventional Cardiology For The Population of
Northern Ireland

Issued by: Health and Social Care Board

November 2012

1.0 Introduction

1.1 The Women's Support Network (WSN) welcomes the opportunity to respond to this consultation.

1.2 The Women's Support Network (WSN), established in 1989, is a regional organisation that works across all areas of Northern Ireland. It includes in its membership community based women's centres, groups and organisations, with a concentration in disadvantaged areas. WSN is a charitable and feminist organisation, which adopts a community development approach. We provide a range of support and services to 63 community based women's centres, projects and infrastructure groups and 26 associate members drawn from across the community and voluntary sector who support women, families and communities. (see Appendix 1).

1.3 Our members provide a wide range of women-centred front line services across Northern Ireland, including:

- Specialist Advice
- Childcare and Family Support
- Counselling, Support and Advocacy
- Complementary Therapies
- Training & Education
- Health & Wellbeing Programmes
- Personal Development & Employment Support
- Volunteering, Leadership & Empowerment

1.4 WSN aims to achieve social, political and economic justice through the promotion of the autonomous organisation of women. The Network aims to strengthen the collective voice of women's groups and to promote and develop networking opportunities, to enable collective action and to impact upon policy and decision making processes. WSN provides an accessible, feminist, relevant and high quality support service and resource for its member groups. The Network is also an important information resource on issues relevant to community based women's organisations and for other infrastructure groups, nationally and internationally.

1.5 Over the past 30+ years, the community based women's sector has developed a range of front-line services such as childcare, support, advice, and education & training services in response to the needs they identified at a grass roots level. Women's groups continue to

meet the particular needs of women and their children living in areas considered to be some of most affected by the conflict, and recognised as some of the most disadvantaged areas across Northern Ireland today.

1.6 Network members are actively engaged with their local communities, cross-community initiatives and regional structures throughout Northern Ireland.

2.0 General Comments

2.1 The Women's Support Network (WSN), as an organisation representing women's centres, projects and infrastructure groups drawn from across the Northern Irish community, welcomes the opportunity to respond to the Health and Social Care Board's consultation on the future commissioning of Paediatric Cardiac Surgery and Interventional Cardiology for the population of Northern Ireland.

2.2 WSN commends the commitment to the delivery of a high quality service for the children of Northern Ireland and would encourage the Health and Social Care Board to ensure that the UN Convention on the Rights of the Child, in particular Article 3 pertaining to the child being the primary consideration, be placed at the centre of this provision. WSN notes that the document is gender neutral and that whilst there are references to recognising the role of parents and the need to make appropriate arrangements for them, that there has been no recognition of the crucial role of mothers in the document.

2.3 In line with Children's Heartbeat Trust's stance on this issue, the WSN considers option 4 to be most appropriate for children in Northern Ireland. An all island networked surgical service extending the relationship which currently exists with Dublin but continuing to maintain the service in Belfast will create a good safe service for all individuals.

2.4 The WSN, while welcoming the reassurances that a high standard of healthcare will be ensured irrespective of the chosen option, believes that there are some issues not sufficiently addressed in relation to the effect this provision may have on women in Northern Ireland, if Dublin or GB is considered to be the most viable option, in spite of strong opposition or if crucially, the services remain in Belfast but a firm relationship with Dublin continues to be established. In Western culture the role of providing care for children

has traditionally been assigned almost exclusively to the mother.¹ Thus, as women provide the majority of informal care to spouses, parents, parents-in-law, children, friends and neighbours², the lack of clarity and necessary detail in parts of this consultation will negatively impact on women. The consultation seeks to be comprehensive and expansive but does not address common contingencies that, if ignored, will be detrimental to the Northern Irish women.

3.0 Specific Comments

Criteria of assessment

3.1 In terms of the criteria of assessment/scoring of generic options, which are proposed for assessing the future provision of Paediatric Cardiac surgery and Interventional Cardiology for Northern Ireland, the WSN is concerned about section four contained therein, if treatment is to be moved from Belfast to either England or Dublin. Section 4 of the criteria covers some very fundamental aspects, namely the ensuring of services which are accessible, in a safe and timely manner, while taking account of and being responsive to the practical and emotional needs of patients and families. Such criteria are surely vital, but they do require concrete back-up to take them beyond the purely aspirational. Though the draft specification provides more information, in that it mentions the need for 'appropriate accommodation' as well as the unspecified and unclear phrase 'other facilities' for parents that travel with children, there is no clear insight given into how best to examine the method most appropriate for dealing with associated costs, which will inevitably arise if treatment is provided outside of Belfast in the future. Accordingly, the WSN calls for clarity on the following issues:

- Whether a specific mode of transport has been recommended in terms of travel to Dublin and GB?
- Whether the HSC or the NHS will cover the costs of travel?
- Whether proper accommodation will be organised?
- Whether there will be suitable accommodation located in proximity to the hospital if travel is required?
- Whether these accommodation costs will be covered?

¹ Hock, E. & Schirtzinger, M. B. (1992). Maternal separation anxiety: its developmental course and relation to maternal mental health. *Child Development*, 63, 93-102.

² Navaie-Waliser, M. Feldman, P. H. Gould, D. A., Levine, C. L. Kuerbis A. N. & Donelan, K. (2002). When the caregiver needs care: The plight of vulnerable caregivers. *American Journal of Public Health*, 92(3),409-413.

- Whether families from deprived areas, unable to afford the cost of eating out and paying additional costs associated with travel for treatment, will be negatively affected?
- Whether the financial burdens, which travelling outside the province for such medical treatment for their children, would put on single mothers and those women not in employment, have been taken into consideration?

3.2 Further clarification relating to the application of Section 4, specifically detailing the approach to be taken if a sick child in need of treatment, has siblings who need to be catered for, should a parent or guardian need to travel with the unwell child for the necessary healthcare, is needed. A report by the Women's Centres Regional Partnership (WCRP) identified lack of appropriate childcare as the single biggest barrier to women's participation in education, training and work, as well as public and political life.³ The WSN suggests that a lack of appropriate childcare is also a potential barrier to allowing women to travel with their children for Cardiac surgery. The report made a number of recommendations, including the development of an integrated childcare strategy for Northern Ireland and increased provision of local, high quality, affordable and flexible childcare. The WSN recommends that, in light of this consultation, it is necessary to also consider the need for appropriate childcare and support if a parent or guardian, who has more than one child, is required to travel with their sick child to receive the necessary treatment. Clearly, the need for some agreement vis-a-vis childcare is intensified in cases involving a lone parent and/or a family containing more than one child.

3.3 Section 4 needs to address yet another knock-on effect implicit in its implementation: the potential problem of inevitable time off work required to travel outside of Belfast. In the current recession and given the high level of unemployment, getting time off work to deal with personal problems becomes increasingly difficult. Thus, if travel outside Belfast is necessary, this becomes a serious issue for mothers in employment. This time burden on women, as primary care-givers, means that faced with the predicament of having to travel to ensure proper treatment for the child, women potentially jeopardise their involvement in the formal employment sector. WSN is also concerned that the stress attached to the worry of losing a job puts a woman's mental health at risk. New statistics confirm that mental illness and depression in women are mostly commonly triggered by stress and anxiety,

³ Woman's Centres Regional Partnership, 2009 'Women living in Disadvantaged Communities: Barriers to Participation'.

fuelled by a broad range of pressures normally relating to family and the struggle to look after young children⁴.

3.4 The issues outlined above, relating to section four of the proposed criteria, arise specifically when the criteria is applied to assess the possibility of Paediatric Cardiac Surgery and Interventional Cardiology being commissioned primarily from Dublin or GB or Dublin and GB.

4.0 An all-Ireland Paediatric Cardiac Service (Generic Option Two)

4.1 One of the biggest concerns of women in Northern Ireland is the fact that their children may not be receiving the proper standard of healthcare. The first criterion proposed for assessing the options for the future provision of Paediatric Cardiac Surgery is that the services commissioned be safe, sustainable and of high quality. However, the WSN is concerned that the current facility in Dublin is not sufficiently adequate. This consultation simply states that a comparable assessment to that already conducted in England has 'not been required or undertaken' in Dublin. WSN feels that this is a very necessary first step in tackling the natural concern of the women in Northern Ireland.

4.2 Furthermore, although the consultation notes that Dublin has 'recently started submitting data to the congenital Cardiac Audit Database' (CCAD) there does not seem to be a culture of normal collection, analysis and reporting of outcome data. This appears to be a relatively new process, confirmed by the consultation's use of 'recently'. Dublin does not currently meet a number of the core Safe and Sustainable Standards, something which has been highlighted in the NI Assembly, despite the failure to conduct an assessment of safety and quality standards. For any mother, the news that her child is seriously ill is a very traumatic experience and the possibility that the standards of the place of treatment may not be up to standard is a concern.

4.3 Nonetheless, this year Crumlin Hospital in Dublin has already treated 20 children from Northern Ireland and continues to take cases considered to be urgent. However, in order to give women of sick child the necessary reassurance, it will be necessary to put a trial period in place to see whether or not this arrangement is the most appropriate.

⁴ Belfast charity New Life Counselling. The charity, which offers free counselling across Northern Ireland, experienced a 23% rise in the number of women accessing their service from 2010 to 2011.

4.4 To travel to another jurisdiction, with a different health and monetary system, is difficult at the best of times. Travelling, due to a serious illness, causes extra, unnecessary stress and hardship. In such a situation parents are expected to uproot and travel away from the natural support base of friends and family at a most vulnerable time in their lives, and to take on the added pressures of loneliness and lack of familiarity with the system into which they are being transplanted. It is obvious, therefore, that issues surrounding the provision of supports including counselling, need to be properly addressed.

5.0 Travelling to England for Paediatric Cardiac Services

5.1 The current health services offered in the UK are in line with the safe and sustainable process. However, the suggestion of travelling to England from Northern Ireland to attain Cardiac Services for children has many pejorative implications for woman.

5.2 Cardiac problems are often diagnosed in infancy. However, when a child is seriously ill and at risk, in the aftermath of birth, the transporting of that child by plane to England is a problematic exercise, potentially fraught with danger; nor is a speedy departure at such a time easy for parents, especially for post-partum mothers, perhaps only a few hours after giving birth. WSN seeks clarity on the issues involving a mother who has had a caesarean section where the child needs a heart operation. In such a situation, with the baby requiring to be flown to England but the mother unable to fly, the very real dilemma of the separation of mother and child and the knock-on effect of such a separation at a crucial time of bonding between mother and child becomes a serious issue. Proximity to a local service would make such a difference in this case. It is noteworthy that, according to the consultation paper, of the children referred to other centres outside Belfast, air or road ambulance was required in half of the cases.

5.3 WSN is also concerned about the provision of care in the case of a baby with a heart abnormality being born prematurely. In this instance, an air ambulance would be required and no member of the family would be entitled to fly. Again, this raises issues relating to separation causing anxiety and worry to the mother. A baby who has had a successful operation can remain in the ICU for three to eight days. However, if there are any unforeseen complications, a baby may be forced to stay in hospital for a much longer period. It is important not to minimise the impact on new mothers of enforced separation from their babies. "Maternal separation anxiety is an unpleasant emotional state of worry, guilt, and sadness experienced by mothers during a short-term separation from their

infant”⁵. While feeling anxious about separation from your child may be normal—and even healthy—for parents of young children, excessive separation anxiety may be maladaptive and detrimental to parents’ mental health, which in turn may have a negative impact on their parenting behaviour and the child’s development⁶.

5.4 Though the consultation paper states that there will continue to be a Paediatric cardiology team in Belfast that will provide on-going care to those who have heart abnormalities but do not need surgery, there is no mention of that fact that if surgery is conducted outside of Belfast that post-operative children will have to return to the centres (either England or Dublin) for a review. This again raises concerns about the separation of mother and child and the strains attached to flying. Clarity is needed as to whether reviews post operation can be done in Belfast, in order to eliminate more flying through a process of referral.

6.0 Conclusion

6.1 The Women’s Support Network would like to see the Health Board take this proposal for future commissioning of Paediatric Cardiac Services for the population of Northern Ireland seriously and to consider the abovementioned difficulties and potential hazards to women if the current services available in Belfast are removed. Why, for example, was Northern Ireland not afforded the same timelines, preparation, or consultation and engagement as England and Wales?

6.2 The WSN feels that the most appropriate option, in terms of what is best for the woman and best for the child, is for the Paediatric Cardiac and Interventional Cardiology services to remain in Belfast. This option will ensure that the services remain accessible to all. However, if the services are to be moved, against the wishes of so many women in Northern Ireland, Dublin appears to be a better alternative to GB. However, the government needs to make the necessary decisions to accommodate and address the inevitable contingencies that will arise and will, doubtless, very badly impact on the women in Northern Ireland. Sufficient funds need to be ring-fenced to tackle issues like transport, accommodation, childcare for the siblings of a sick child and employment cover for a leave of absence. Due consideration has to be given to the very real possibility that women will be very anxious and worried in the event of having to undertake any form of travel and issues like stress and depression may become a very big problem.

⁵ Mckenna, J. (1996) ‘Babies Need their Mothers’, *World Health*, World Health Organisation.

⁶ Ibid

6.3 The WSN fully endorses the arguments of the Children's Heartbeat Trust and urges the Health board to ensure that the child is paramount when any decision is to be taken.

6.4 The WSN believes that Key Performance indicators, which measure success in achieving specific goals and targets, are needed to best assess the safest and best quality approach to paediatric cardiology services for Northern Ireland.

6.5 In tackling the issues of accommodation and support for the mothers of sick children that this response has highlighted, the recognition that NGOs and voluntary groups of various kinds are good at developing innovative approaches based on realistic picture of what is actually needed is also important and not to be ignored. The HSBC could also look to programmes like the Ronald McDonald House programme, which provides a "home-away-from-home" for families so they can stay close by their hospitalised child at very little cost and attempt to find a concrete solution to the basic problems associated with asking any family to move to receive healthcare.

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MEMBERSHIP 2012

| | <u>Member Group</u> |
|----|--------------------------------------|
| 1 | All Ireland Mother's Union |
| 2 | An Munia Tober (Travellers) |
| 3 | Antrim & Ballymena Women's Aid |
| 4 | Ardmonagh Women's Group |
| 5 | Ardoyne Women's Group |
| 6 | ATLAS Women's Centre |
| 7 | Al Nisa Women's Group |
| 8 | Ballybeen Women's Centre |
| 9 | Ballymurphy Women's Group |
| 10 | Belfast & Lisburn Women's Aid |
| 11 | Belvoir Women's Improvement Group |
| 12 | Carrickfergus Women's Forum |
| 13 | Carew II |
| 14 | Causeway Women's Aid |
| 15 | Chrysalis Women's Centre |
| 16 | Clan Mor Women's Group (Sure Start) |
| 17 | Derry Well Woman |
| 18 | Derry Women's Centre |
| 19 | Falls Women's Centre |
| 20 | First Steps Women's Group |
| 21 | Footprints Women's Centre |
| 22 | Foyle Women's Aid |
| 23 | Foyle Women's Information Network |
| 24 | Granaghant District Women's Group |
| 25 | Greenway Women's Centre |
| 26 | Kilcooley Women's Centre |
| 27 | Lesbian Advocacy Services Initiative |
| 28 | Lesbian Line |
| 29 | Lenadoon Women's Group |
| 30 | Ligoneil Family Centre |
| 31 | Link Women's Group |
| 32 | Manor Women's Group |
| 33 | Markets Women's Group |
| 34 | NI Women's Aid Federation |
| 35 | NI Women's European Platform |
| 36 | Fermanagh Women's Network |
| 37 | Newry & Mourne Women |
| 38 | Newtownabbey Women's Group |
| 39 | Older Women's Network NI |
| 40 | Omagh Women's Aid |
| 41 | Rape Crisis Centre |
| 42 | Rasharkin Women's Group |
| 43 | Shankill Women's Centre |
| 44 | Strabane & Lifford Women's Centre |
| 45 | Strathfoyle Women's Centre |

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| 46 | The Learning Lodge |
| 47 | Voices Women's Group |
| 48 | Waterside Women's Centre |
| 49 | Windsor Women's Centre |
| 50 | Women Connect Project |
| 51 | Women into Politics |
| 52 | Women's Information Group |
| 53 | Women's News |
| 54 | Women's TEC |
| 55 | Women 2 Gather |
| 56 | Women's Resource & Development Agency |
| 57 | WISPA (Women in Sport & Physical Activity) |
| 58 | Ardcarn Women's Group |
| 59 | OIYIN Women's Group |
| 60 | Mossley Women's Institute |
| 61 | Mount Vernon Women's Group |
| 62 | Coole New Opportunities |
| 63 | North Belfast Womens Initiative & Support Project |
| | <u>Associate Members</u> |
| 1. | Ballymena Community Forum |
| 2. | CiNI |
| 3. | Community Relations Forum |
| 4. | East Belfast Community Partnership |
| 5. | Employers for Childcare |
| 6. | HIV Centre (Women's Support Group) |
| 7. | Mencap |
| 8. | National Women's Council of Ireland |
| 9. | Playboard |
| 10. | RNIB (Women's Group) |
| 11. | Good Morning Newtownabbey |
| 12. | Monkstown Community Association |
| 13. | WAVE Trauma Centre |
| 14. | WEA |
| 15. | Parents Advice Centre |
| 16. | Templemore Community Action Group |
| 17. | Gingerbread |
| 18. | Larne Community Development Project |
| 19. | Community First Coaching |
| 20. | Changing Faces |
| 21. | Sands NI |
| 22. | Women's Project Ashton Centre |
| 23. | Women on Track |
| 24. | Matt Talbot Women's Group |
| 25. | Ulster People's College |
| 26. | Council for the Homeless NI |