



**CHILDREN'S
HEARTBEAT
TRUST**

Northern Ireland's
Children's Heart Charity

Charity no: NIC 102410

Organ and Tissue Donation (Deemed Consent) Bill Call for Evidence

24th September 2021

Children's Heartbeat Trust is a local charity that provides support to children, young people and families living with Congenital Heart Disease (CHD) in Northern Ireland. CHD is the most common birth defect in the world, and over 200 babies are born with CHD here each year. A small number of the children we support will require heart transplants with organ donation offering their only hope of survival.

In sum, Children's Heartbeat Trust is fully supportive of the Organ and Tissue donation (Deemed Consent) Bill. We are hopeful that it will increase the current rate of consent in the small number of cases in which it is clinically possible for organ donation to proceed after a person's death. We are particularly encouraged by the policy's overall objective to promote a positive cultural and long-term change in attitudes and behaviours to organ donation. However, whilst the proposed Bill affects adults only, it is imperative that this cultural and long-term change includes a shift in perspective to the donation of children's organs.

Children's Heartbeat Trust notes that 47.78% of respondents to question five in the consultation either strongly agreed or agreed that the opt-out legislation should not apply to children (those under 18). This means the majority either disagreed, strongly disagreed or neither agreed or disagreed. Heartened by this and through our work with teenagers and older children, it is our firm view that at age sixteen individuals have the capabilities to develop a robust understanding of the complexities of organ donation and thus make a fully informed decision regarding their own organs. As such the legislation should apply to age 16 and over.

- **“Appropriate consent” to adult transplant activities.** Children's Heartbeat Trust is of the opinion that the new legislation should apply to persons aged 16 and over.
- 1. (7) Children's Heartbeat Trust is satisfied that at least once a year the public are given information regarding the effect of legislation about deemed consent and information about how to record their decisions or appoint someone to make decisions of their behalf. However, if all children under 18 are to remain exempt, Children's Heartbeat Trust strongly proposes that any public awareness campaign explicitly communicates how children can be added to the organ register. Children who need transplants deserve no less.

Sarah Quinlan, Chief Executive of Children's Heartbeat Trust, is available to give oral evidence to the committee if required.

Children's Heartbeat Trust

Howard Building, HF10
Twin Spires Centre
155 Northumberland St
Belfast
BT13 2JF

T. +44(0)28 9031 2228
E. info@childrensheartbeattrust.org