HEALTH AND SPORT COMMITTEE

HUMAN TISSUE (AUTHORISATION) (SCOTLAND) BILL

SUBMISSION FROM CHILDREN’S LIVER DISEASE FOUNDATION

1. What do you think are they key strengths and weaknesses of the proposals to introduce 'deemed authorisation' for those who have not made their wishes on organ donation known?

Strengths:

Potential for increased numbers of donors as it allows donation to become the default position. Reduces the gap between intent and action.

Inclusion of duty of Scottish ministers to promote information and awareness regarding how authorisation of transplantation may be deemed to be given

Inclusion and emphasis on relatives

Use of “relevant time” instead of “immediately before an adult’s death”. Timing is key when having discussions with relatives and this may provide healthcare professionals with more flexibility about how to approach family. It is also made clear when this “relevant time” may be.

Considers the rights of vulnerable groups – those who may not understand the nature and consequences of deemed authorisation. However, are these discussions undertaken with vulnerable group for a relative to be able to know their views?

Weaknesses:

Still a reliance on family members consent even if the individual has not opted out if they can prove that the individual objected to donation but had not recorded this or if there is evidence that they were not capable of making that decision. Also, it is not clear if the relative would have to raise that discussion with the health worker or if they are consulted during the process.

Those who do not wish to donate may not have had an opportunity to opt-out in time or mention it to relatives. They would be considered willing donors.

Regarding awareness and promotion, individuals often do not want to discuss death or preparations for it due to fears, religion, culture, ‘tempting fate’ etc. Therefore, will they engage or listen to messages being communicated?

Affects every individual regardless of language and culture so must consider communication techniques as if the bill is passed and family members are not aware of this it will have a major impact on their emotional wellbeing during an already challenging time.
2. What do you think are the key strengths and weaknesses of the plans for authorisation of pre-death procedures?

Strengths:

Clear definition of what is meant by pre-death procedures and types.

Duty to promote information and awareness about the nature of pre-death procedures, when they may be carried out and how they may be authorised.

Inclusion and discussion of relatives in the Bill as it will have an emotional impact on them during a very distressing time.

Weaknesses:

Reliance on relative to authorise pre-death procedures and as a result if they are aware of evidence that shows that the individual was opposed to this they may refuse authorisation. This can lead to donation not being made as pre-death procedure not able to take place.

3. Do you have any other comments to make on the Bill?

It has been recognised for some time that the UK compares poorly in terms of donation rates with other countries in Europe. This soft-opt out approach may potentially increase the number of donors in Scotland.

Deemed consent is already in place in Wales and consultations taking place in England. CLDF are pleased that there will hopefully be consistency across all areas of the UK in the near future.

CLDF supports any system which increases the number of organs available for donation, but we need to consider the importance of family consent as donation cannot take place without this even with deemed authorisation. Even though 23 million have signed up to the organ donation register only half have discussed their wishes with their families. Therefore, it is vital for families to have discussions about individual wishes even with deemed authorisation or opt-out systems in place.

Children's Liver Disease Foundation (CLDF) is the only UK charity dedicated to fighting all childhood liver diseases. We do this by providing information to families and to health professionals, emotional support to young people with liver disease and their families, funds for research and a voice for all affected.