



Lynne Neagle AM,
Chair of Children, Young People and Education Committee National Assembly for Wales
Cardiff Bay
Cardiff
CF99 1NA

8th January 2020

Dear Lynne Neagle AM,

We wish you a happy new year and would again like to thank you for giving us the opportunity to take part in your children's rights inquiry.

We would like to update you that we have still not received the information we requested from the Welsh Government regarding decisions the Government has made that affect children with complex health conditions. We are wondering if you can assist us in your scrutiny role in helping us to access this information or whether at this point in the inquiry you advise us to pursue this information through another channel?

We accessed the information provided by the Deputy Minister on December 10th (Letter from Deputy Minister for Health and Social Services to NAFW Children and Young People Education Committee) regarding the published CRIAs and there is no evidence on the Welsh Government website to indicate that a CRIA has been undertaken:

- into the review of the Activity Based Funding Model;
- or as part of the decision making regarding the significant amount of public funds that will be spent on the health and social care research infrastructure by the Welsh Government 2020-2025.

Additionally we still have not been able to access evidence on the Welsh Government's overall spending on clinical paediatric research support and delivery. As per our earlier evidence, Welsh children are not receiving the same opportunities as adults or indeed children in England to participate in vital clinical research.

These decision-making processes have a significant bearing on whether the human rights of children with complex health conditions are being respected, protected and fulfilled and this information should be made urgently available.

We also have concerns that this may not be an isolated case and that there may be a number of other Welsh Government decision making processes that have not been subjected to the robust scrutiny that having due regard to children's human rights requires.

We would therefore welcome your Committee making strong recommendations for a thorough review of all Welsh Government decision making; to ensure that all officials and Ministers are subject to rigorous and mandatory training regarding understanding fully their children's human rights obligations and the appropriate systems of accountability are in place and enforced.

We look forward to receiving your response and any advice you can offer us going forward regarding accessing the information we have requested.

Yours sincerely

Dr Phillip Connor,

Rhian Croke

Rhian Thomas-Turner