Dear Members of the Equalities and Human Rights Committee,

dsfamilies is a Scottish (and UK wide) Charity supporting children, young people and their families who are born with different sex development (DSD). DSD (which is sometimes known as intersex) affects sex hormones and reproductive organs: every year in the UK, approximately 150 children (around 12/year in Scotland) are born with genital difference or mixed sex characteristics. That means there are approximately 2,300 children living with DSD conditions in the UK. We work together with families and their children, teens and young adults, and healthcare providers in the UK to raise happy, healthy, confident and well-informed young people who can speak up for the support they need.

As evidenced in our ground-breaking report ‘Listen to Us’, what children, young people and their families - as well as adults and healthcare professionals – want and need is some of the most basic yet unmet support:

- Psychological and educational support, especially information about a child’s condition: what it is; how it happened; how to support the child.
- Support to talk to their growing child and to partners and friends; peer support to address the isolation that is rife in this cohort of people and families (often creating anxiety and stress for parents and children)
- Opportunities to connect with other families in similar situations.
- Healthcare professionals who can talk and care sensitively about the range of issues that matter.
- Positive public engagement, no misrepresentations.

Unfortunately, DSD conditions are still poorly understood and badly represented. dsfamilies has been working with Scottish Government officials and MSPs since early 2017 to try to correct some basic misinformation and to try to encourage better and targeted support. Unfortunately, we are sorely in need of resources, while all government funding for intersex projects to date has been awarded to LGBT groups.

Despite the lack of funds, since 2011 dsfamilies have built an international reputation for resource development: we have produced information on the different conditions which are used by families and healthcare professionals and our booklet “when your baby is born with genitals that look different” has been translated into 15 languages. We help facilitate one-to-one counselling and support as well as family days to support young people and families. We also attend professional events and inform policy in Westminster and Holyrood. We work closely with NHS Scotland, NHS England, with the BSPED DSD SIG, our chair of trustees chairs the British Psychological Society’s DSD SIG. We are currently producing a booklet to explain the biological process (the story) of sex development which will enable health professionals and parents to explain in a sensitive and accessible way how a child developed. Our trustees include parents and professionals and advise the NHS and the European council.

Our report “Listen to US” is the only comprehensive study of children and young people to date and reinforced the message that there is a need for proper psychological support; better information; opportunities to connect; and tools to talk about and explain diagnoses. A diagnosis of DSD can be an isolating experience,
made worse as those with such conditions are increasingly misrepresented for different political ends or financial and strategic gain.

We are therefore saddened that the only funding from Scottish Government to a third sector organisation was a five year grant of £45K p.a. awarded to Equality Network in 2015. FoIs revealed that the Scottish Government believed that Equality Network were “the only organisation in Scotland who had begun to look at the issue”¹. dsdfamilies was established in 2011 and largely operated from Scotland. Because the bid was below the £50k procurement threshold there was no need for competitive tendering.

We are concerned that the budget for DSD work has been given to an organisation which, we believe, has not done prior work on DSD. We are also concerned that their focus is, we believe, not appropriate for children and individuals affected by DSD.

Despite this five year award, in December 2018 the Equality Network have said their work on DSD is “at a very early stage”.² Their focus has been on the visibility of individuals, which is not always appropriate, especially for children - also some of the loudest voices are not the most representative. The value of ‘visibility of intersex’ is questionable if those living with it are not given the support to build on any kind of visibility or are supported to negotiate it. Who does this benefit?

We also noted with concern that, for a long time, the stated aim on Equality Network’s webpage was to “challenge the definition of sex as consisting only of male and female and promote the knowledge that sex is on a continuum”. This was removed shortly after a parliamentary question about it this year³. However, we remain deeply concerned. Much of our work with young people is to reassure them that they are not “other” and that they are not excluded from their sex category because of infertility or, for example, smaller male genitals. We do not think it appropriate for a Government funded group to promote what we perceive to be the damaging message that a child is not a “real” boy or girl simply because they have differently shaped genitals.

We are now increasingly being called upon by the Scottish Government to assist in ensuring that output in this area is accurate. This is hard when we do not have paid staff. We should also like to focus on building proper support networks and communication channels, which our children, young people and families really need. We are also discussing how we can build this model for adults with DSD conditions.

We believe that there has been a massive category error with regard to considerations of DSDs on the part of the Scottish Government. Most of the key areas we identify relate to healthcare and psychological support and yet the Government continues to regard it as an identity issue. We believe opportunities been missed and children left unsupported, and much damage has been done. We

³ https://www.parliament.scot/parliamentarybusiness/28877.aspx?SearchType=Advance&ReferenceNumbers=S5W-23930&ResultsPerPage=10
should very much like to see a process in future awards of funding and targeted help for the appropriate demographic.

dsdfamilies