



# “I wouldn't want her involved in anything like that”

## Parents' concerns about children's involvement in DSD research

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## Background and Method

Children should collaborate in research about their health conditions. Differences of Sex development (DSD) research has been criticised for promoting views of parents and health professionals only<sup>1</sup>. However parents are concerned about professionals talking to children about sensitive subjects including fertility and sexual activity. Children may have little experience of talking about their sex development. This makes direct research involving children with DSD particularly challenging.

<sup>1</sup>Schober, J. Nordenstrom, A. Hoebeke, P. Lee, P. Houk, C. Looiejenga, L. Manzoni, G. Reiner, W. Woodhouse, C. Disorders of Sex Development ;Summaries of long term outcome studies Journal of Pediatric Urology November 2012

As part of a UK interview study with 27 parents of girls with CAH, we asked about the possibility of involving their children directly in research. We tried out a questioning technique via one to one interviews with 4 young people (aged 11-15).

We used our ethically approved indirect questions regarding access to leisure and social activities (swimming and sleepovers) to address the fears of new parents. The youngest of the girls appeared most comfortable recalling her enjoyment of these activities. The older girls seemed ready to talk about their condition in a way that we did not have ethical approval to pursue. The brief interviews demonstrated that two of the girls had little awareness of any genital difference, despite significant parental concern. One girl with greater awareness of her genital difference, had minimal concern and believed that future surgical alteration is available to her if required. Two girls noted their positive experience of romantic pairing.



*“I wouldn't want her involved in anything that ... I just wouldn't want to draw attention to it...I don't want to make her self-conscious. I don't want to make her suddenly realise that she's different at this age..and I would worry that anyone speaking to her..would make her start questioning and worrying, and yeah, it's not something I'd....I can't see how you can speak to children and get the answers you want without actually asking them the questions...I think this would be quite an alien thing for her anyway, to be sat down and talked at and asked questions.”*

(Parent of a 7 year old girl with CAH )

These barriers to children's participation in DSD research echo the same parental fears seen in a wider study about management of genital difference in DSD. Unless clinical teams support parents fully, these fears may impede children's essential understanding of their diagnosis. This is because parents actively avoid childhood awareness of genital difference. Adults tell us<sup>2</sup> they regret the lost opportunity of growing up with an awareness of their body and the preparation that affords.

<sup>2</sup> Alderson, J. Madill, A. Balen, A. British Journal of Health Psychology 9(Pt 1):81-100 2004

## ADVICE FROM PARENTS ABOUT CHILD PARTICIPATION IN RESEARCH

- Using a researcher known to the child or enabling the child to become comfortable with the researcher
- Neither a hospital or domestic location
- Use of online questionnaires
- Awareness of all research questions prior to involving their child.
- Involve older children only
- Use direct questions
- Use indirect methods

## STUDY THEMES ABOUT PARENTAL BARRIERS TO CHILDREN'S PARTICIPATION

**Worry too soon:** Parents fear that taking part in research will raise their child's concern about their condition prematurely

**Awareness of difference:** Parents worry that participation would make their child aware that they are different from other children

**Talking to friends:** Parents are concerned that having spoken to a researcher, completed a survey or a questionnaire, the child might then go on to talk about to their friends about their condition.

## Conclusion

This varied advice from parents highlights the need for creative patient and parent co-design, in studies involving children. The mode of children's research participation needs to be negotiated.

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