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. 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.


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.

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 an 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 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.

Declaration: Julie Alderson is Chair of Trustees of the UK Charity dsfamilies.

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“I wouldn’t want her involved in anything like that” Parents’ concerns about children’s involvement in DSD research

Julie Alderson, Maia Thornton, Nicky Nicoll, Julie Jones, Mars Skae, Elizabeth Crowne


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