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The Chicago Consensus - a patient perspective

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Abstract

From the consumer perspective, Chicago was a historic conference. It was the first time that advocacy group members were able to take full part and articulate concerns in a conference of this kind which also clearly acknowledged the role of support groups.

Some highlights:

The focus has shifted from preoccupation with gender identity issues (which have dominated past debate) to a greater emphasis on quality of life, where sex seen as far more than genital function, to an awareness of the need for an individual approach to treatment, and to a clear acknowledgement of human ignorance about gender identity and of the huge shortfall in evidence justifying present treatment methods, often based on the simplistic view that there is a „true sex“. Seeing DSDs less in splendid isolation and more like other childhood medical conditions can provide valuable insights into improving the quality of practice and care.

Past terminology has been misleading and inaccurate, discriminatory and the cause of much distress. The new terminology avoids this, explaining individual conditions as precisely and as understandably as possible. „DSD“ is more descriptive of ALL conditions with problems in the complex development of the uro-genital tract than „intersex,“ and only describes the biochemical/anatomical reality of a human being and not the person as a whole. It makes no predictions about identity, or about social and sexual behaviour. The more inclusive term "DSD" explains why conditions like AIS, MRKH, CAH, Turner, Hypospadias etc. belong together; viewing them together also makes it harder for health-care systems and funding bodies to ignore the group's medical needs. However, there are concerns that DSD still pathologizes too much; in the German word "Störung", the overtones of being „disturbed“ are not helpful.

Long-term care provided by multidisciplinary teams and centres of excellence instead of amateur „lone rangers“ is to be the model for better quality patient-centred care everywhere. Informed consumers and the internet will ensure that competition leads to higher standards.

The importance of respect of confidentiality, open communication with those affected and their families and their increased participation in decision-making process are all highlighted, as is the pivotal role of professional counselling as an

on-going process. The trauma caused by medical interventions, photography, display, etc. is acknowledged, but also the increased psychosocial adaptation of children with other conditions who know the truth about their conditions.

The growing tendency to no longer operate on an enlarged clitoris is emphasized. Hence Prader I und II are not be „corrected" at all in future, nor are vaginal dilatation or gonadectomy in AIS to be carried out before puberty. Assuming parents are more likely to accept children if cosmetic, genital surgery has been carried out was described as a "belief" in Chicago, not yet substantiated by long-term outcome studies, (which I think should generally be carried out by independent bodies, not by the care-providing institutions themselves). More watchful waiting and preservation of tissue whenever possible would also be preferable, as would stronger condemnation of secrecy and dishonesty about conditions when talking to those affected.

I hope in future for increased fruitful contact between professionals and support groups, joint preparation of conferences and other joint ventures (like "Guidelines" by US Consortium) which focus on more providing better medical care, thus increasing the number of satisfied consumers.