

Report to AISSG on Chicago Consensus Conference October 2005

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Not a conventional conference

- 2½ days
- Emphasis: Work in small theme-based study groups in English
- Review of „evidence-based“ (representative) studies, no suppositions or anecdotal evidence admissable
- Participants (about 50 experts from 10 countries) invited by group leaders (6-7 per group)
- **Plus Cheryl Chase (founder and director of ISNA) and me**

The study groups

1. Recent Molecular Genetic Impact of Human Sexual Development
2. Brain Programming by Genes and Hormones (evidence -based)
3. Investigation and Medical Management of Intersex in the Infant, Child and Adolescent
4. Surgical Management of Intersex
5. Psychosocial Management of Patients with Intersexuality and Related Conditions
6. Outcome Data: Evidence-based

Approach

- Group members were assigned a key question in advance and asked to write a statement as a basis for group discussion
- Results of all group papers were discussed in the groups, overlap eliminated, and a group document produced
- Group documents presented in plenary session and comment invited
- Second phase of group work: reduction of group documents to 1,500 words (!)
- Final plenary session
- Editorial team summarizes group documents and produces single text with a view to publication in medical journals

1. Now changed to www.aissg.org. See also footnote on page 2.

Role of members of advocacy/support groups

- Cheryl was in group 3 (Investigation and Medical Management of Intersex in the Infant, Child and Adolescent)
- I was in group 5 (Psychosexual Issues)
- I was invited by Heino Meyer-Bahlburg (Columbia Univ, NY) who chaired panel discussions at Halle and Lübeck in 2004, where I also spoke¹
- There were no members of advocacy/support groups in group 4 (surgery)
- We were not given a question to write on, but were invited to comment on what the members of our groups had written.
- We took part in the plenary sessions.

What was it like?

- Extremely strenuous – work from morning, sometimes till midnight, mostly in groups, in windowless rooms in airport hotel, with jetlag!
- No cultural programme, sightseeing etc, by the way, just work!
- Participants were very diligent and highly motivated
- Atmosphere was collegial
- Complexity of issues often hard to grasp, and huge amount of information to process in a very short time
- Difficult for Cheryl and me to be alone – are we missing something? Do we need to insist more?
- Cheryl and I tried to liaise, share, discuss etc. as often as possible in breaks between sessions
- Useful discussions with other delegates, e.g. with Garry Warne

Garry Warne – Recommendations which are of relevance to affected adults

- Suggestions made to avoid use of discriminatory and hurtful terminology (e.g. male pseudohermaphrodite)
- Terminology should serve to explain the individual condition as precisely and as understandably as possible (e.g. analogous to AIS in the place of testicular feminisation or male pseudohermaphroditism)
- Every affected individual should be viewed as an individual, avoiding generalisations
- Terminology for the phenomenon as a whole should only make a statement about the biological reality of a human being and not about the person as a whole, as a social being or about identity, gender roles etc.

1. Although Barbara, who lives in Germany, is a long-standing member of AISSG UK, she was invited to the conference on a personal one-to-one basis in this manner, and not as a representative of AISSG. AISSG was not aware of the conference until Barbara mentioned she'd been invited, and on emailing the US organiser to ask what was on the agenda, AISSG received a short response saying there was no set programme and that the conference was by invitation only.

- Dissatisfaction with the term „Intersex" (confusion with TS / more than a statement on biological reality)

DSD (Disorders of Sex Development)

- Already used in Clinical Guidelines and Handbook for Parents by Consortium on Management of DSD, produced by affected adults, medics and parents and given to all delegates in Chicago. It can be accessed via ISNA website or www.dsdguidelines.org
- Term ‚disorder' has unfortunate overtones of „disturbed" in German translation, however, given the reluctance of health insurance firms to deliver the goods to intersex customers, the more PC [term] „variation" is not helpful when campaigning for better care.

Quote from Handbook for Parents, p.68-69

„Because there are so many stages of sex development in human life, there are lots of opportunities for a person to develop along a path that isn't the average one for boys or girls. When a less common path of sex development is taken, the condition is often called a disorder of sex development or DSD."

Further proposals

- Long-term care provided by multidisciplinary teams instead of „lone rangers"
- „Centres of excellence" - instead of amateurs „having a go"
- Open communication with those affected and their families is essential
- Facilitate participation of those affected and their families in decision-making process
- Respect of confidentiality
- Emphasis on the importance and impact of the first encounter with the family/ affected individual
- Emphasize the potential of the child
- Acknowledgement of the role of support groups
- Statement on the role of support groups included in appendix of final document (we were invited to write a text spontaneously for this purpose during the final plenary session)
- Link to www.dsdguidelines.org (Handbook for Parents and Clinical Guidelines written by consortium of ISNA members, parents and doctors) in final document
- Acknowledgement of trauma caused by medical interventions, photography, display, etc.
- Photography should only be carried out with consent and if absolutely necessary, should be carried out when a surgical intervention with anaesthetic is taking place

Surgery

- The responsibility of surgeons to explain consequences of surgical interventions for childhood and adulthood is emphasized

- Only experts should operate
- The growing tendency to no longer operate on an enlarged clitoris is emphasized
- Prader I und II should not be „corrected" at all
- It is not proven that parents are more likely to accept their children if cosmetic, genital surgery has been carried out, even though many studies maintain that this is the case
- No vaginal dilatation before puberty
- Gonadectomy in AIS can wait till puberty (earliest documented malignancy in CAIS at the age of 14)
- Statement in consensus document recommending automatic removal of gonads in PAIS and CAIS (protested at in and after Chicago) is extremely disappointing, however, elsewhere the document says that:
- Potential for gonadal malignancy in various conditions can be predicted more accurately now (publication L. Looienga, Rotterdam)
- ERGO: Check potential for malignancy with biopsy before removing gonads

Psychological issues

- Psychosocial care by competent experts should be an integral part of an ongoing process
- It should be a flexible, individual-based approach
- Sufficient time should be accorded to sessions with parents and those affected to ensure that information has been understood and to deepen understanding of the issues.
- Families who are at risk for maladaptive coping with child's condition should be identified and given extra support
- Psychosocial adaptation of children is enhanced by disclosure
- Medical interventions can cause post-traumatic stress disorder and intimate examinations may be experienced as deeply shaming
- Opportunities to discuss fears and worries about how to approach and deal with sexual encounters
- Sex therapy should be offered if desired

Open questions

- We know very little about gender identity
- Data on long-term outcome and satisfaction are inadequate
- In some cultures, economic factors play a special role in decisions about sex assignment (e.g. social ostracism and economic destitution in some societies for single, intersex women)
- Satisfaction with early and late surgery needs to be evaluated on a holistic basis
- Suppositions and speculation are not a good basis for medical interventions

Limitations of the conference

- Participation by invitation only – invitation criteria??
- Input from those not invited could have been garnered in advance
- Limitation of what was discussed by the way questions to be answered by group members were phrased
- Editing process in and after Chicago inevitably causes a reductionist view of things
- Too little time: virtually no time for discussion with other delegates in other groups apart from at meals (some of which also taken in groups!)
- Disappointing statement on gonadectomy in AIS
- More participation of advocacy and support groups would have been desirable (especially in group on surgery) – BUT: Many doctors still seem to question the ability of support groups to enter into constructive dialogue and hesitate to recommend them (fear of a lunatic fringe?)
- The final document does not write recommendations in stone, and should be seen as an instrument to provoke further discussion.
- Should members of advocacy groups accept invitations to take part in conferences of this kind? - I think that it is a step forward to do so, but expectations should not be too great. How much weight would 2 medics have in a consensus conference with 50 support group experts?
- Dialogue between support groups and the medical profession should be intensified further