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The Chicago Consensus - a patient perspective

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A historic conference

- It [Chicago consensus meeting Oct 2005] was the first time that members of support/advocacy groups were invited to participate in a conference of this kind.
- Cheryl Chase and I were able to take full part in the conference as equals in an atmosphere of collegiality.
- Many consumer criticisms about treatment were addressed.
- The focus has broadened from the preoccupation with gender identity issues in past debate.
- The Consensus document makes it clear that sex-assignment does not inevitably mean surgical intervention.
- The huge shortfall in evidence justifying treatment methods is acknowledged.
- Every case needs to be dealt with on its own terms.

Recommendations for improvement of care

Terminology

- Terminology was proposed which is not misleading to professionals or lay people and which explains the individual condition as precisely and as understandably as possible (e.g. AIS versus testicular feminisation) .
- Avoid use of discriminatory terminology which also causes distress! (e.g. male pseudohermaphrodite / testicular feminisation).

DSD

„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.“

From: Handbook for parents, p.68-69, Consortium on Management of DSD, (by affected adults, medics and parents) www.dsdguidelines.org

For DSD

- The term is clearer and more descriptive than „intersex" of ALL conditions with some problems in the highly complex development of the uro-genital tract.
- „DSD" includes conditions which belong together (e.g. MRKH, CAH, Turner, Hypospadias etc.) - „Intersex" was an inappropriate and unacceptable term to many people with these conditions.
- Terminology for the phenomenon should only make a statement about the biological reality of a human being and not about the person as a whole, nor should it make statements or predictions about behaviour as a social or sexual being or about identity, gender roles etc.
- Given man's huge ignorance on gender identity issues, the new terminology, which expresses only a *biological* reality, is less likely to tempt practitioners into making treatment decisions beyond their field of competence, based on speculations about gender identity outcome.
- Transsexualism and Intersex are no longer so easily confused.
- Given the reluctance of health insurance/ health care systems to provide optimal care and sufficient psychological support to intersex customers, the larger the number of conditions bracketed together the better.
- The more PC [term] „variation" is not helpful when campaigning for better care.

...and against DSD

- Unnecessarily pathologizing the phenomenon has proved deeply harmful to those affected and their families, making self-acceptance additionally difficult. The term DSD may not go far enough to counteract pathologization.
- The word „disorder" has unfortunate negative overtones of „disturbed" in German translation, STÖRUNG.....
- Acronyms like „DSD" are rather abstract.
- In the process of coming to terms with their conditions since the phenomenon has been in the open, some consumers have become very attached to the term „intersex".

Further patient-friendly proposals

- Long-term care should be provided by multidisciplinary teams instead of „lone rangers".
- „Centres of excellence" - instead of amateurs „having a go"
- The importance and impact of the first encounter with the family/ affected individual is emphasized.
- Open communication with those affected and their families is essential.
- Participation of those affected and their families in the decision-making process should be facilitated.

Practitioners should emphasize the *potential* of the child (not what is lacking...!)

- The role of support groups is acknowledged.
- A statement on the role of support groups is included in appendix of final [Chicago consensus] document. (We were invited to write a text spontaneously for this purpose during the final plenary session.)
- A link to www.dsdguidelines.org is provided. (Handbook for parents and Clinical Guidelines written by consortium of ISNA members, parents and doctors)
- The trauma caused by medical interventions, photography, display, etc. is acknowledged. (NB: vaginal dilatation)
- 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.

Recommendations on 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 avoid operating on an enlarged clitoris is emphasized.
- Prader I und II should not be „corrected" at all.
- No vaginal dilatation before puberty!
- The [Chicago] document emphasizes that there is no evidence that parents are more likely to accept their children if cosmetic, genital surgery has been carried out, even though this belief is widespread.
- Gonadectomy in AIS can wait till puberty (earliest documented malignancy in CAIS at the age of 14).
- The statement in consensus document recommending automatic removal of gonads in PAIS and CAIS is extremely disappointing.
- However, the document says elsewhere that potential for gonadal malignancy in various conditions can be predicted more accurately now (publication L. Looijenga, Rotterdam).

Psychological issues

- Psychosocial care by competent experts should be an integral part of an *ongoing* process (i.e. in childhood, adolescence, adulthood, relationships, parenting).
- It should be a flexible, individual-based approach. Families who are at risk for maladaptive coping with their child's condition should be identified and given extra support.
- 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. (i.e. emphasis on what recipient has *really* understood, not what professionals *think* or *hope* they have communicated)

- Psychosocial adaptation of children is enhanced by disclosure (evidence from other conditions that knowledge of their condition empowers children and increases self-confidence).
- Medical interventions can cause post-traumatic stress disorder and intimate examinations may be experienced as deeply shaming.
- The document recognizes that there are many more psychological issues for those with DSDs to deal with than just genes, gender identity and genitals.
- Opportunities to discuss fears and worries about how to approach relationships and deal with sexual encounters should be provided.
- Sex therapy should be offered if desired.

Where do we go from here? - wishes for the future

- Multi-disciplinary approach is essential, but more emphasis on *patient-centred* care is required. This means understanding patients' needs better.
- Regional centres of excellence should be the norm, the more of them the better. Patients will choose the best quality care and recommend centres where the teams work best together.
- Competition within a team should be avoided, as it undermines the patient's trust.
- Team building and training of medical, mental health professionals, nursing and midwifery personnel urgently need to be expanded.
- Nomenclature changes signal a change in fundamental *attitudes* to and *assumptions* about the phenomenon - BUT these attitudes and assumptions urgently need to be re-examined, too... Having a DSD is not the end of the world!
- ...and it is certainly not a reason to terminate a pregnancy!
- We can learn more from medical practice in other disorders, instead of viewing DSD in splendid isolation.
- Secrecy and the practice of lying to patients and their families need to be condemned in much stronger terms.
- „We are as sick as our secrets.“ (Alcoholics Anonymous)
- Links to support groups should be provided in publications like the Consensus document.
- It should be common practice to inform parents about support groups' existence and not prejudge the experience that they will make there. Most parents are particularly grateful for the end of isolation and are perfectly capable of judging what members' input is helpful in their situation and what is not.
- Suppositions and speculation are not a good basis for medical interventions: Much more long-term outcome-based research is necessary.
- Outcome-based research should preferably be carried out by independent bodies, not by the care-providing institutions themselves.
- The more cautious approach to childhood cosmetic surgery is a step in the right direction, but more evidence of long-term satisfaction is needed to justify the

practice of childhood cosmetic surgery and to document the advantages of watchful waiting.

- *Preservation of tissue and integrity of the body should be given greater priority.*
- The practice of automatic gonadectomy in CAIS should be ended.

Conferences

- Planning of consensus (and other) conferences with input from consumer groups would increase consumer acceptance of results.
- Involving consumers in the formulation of questions for discussion or inviting pre-conference input from those who have not been invited would be useful.
- There are still far too few occasions and opportunities for dialogue and exchange of views between practitioners and affected adults. We hope to be included more often in the future.
- It was a huge burden of responsibility for 2 people to be the sole consumer representatives in a conference of 50+ practitioners - more consumer representatives desirable, especially in areas of greatest controversy (surgery).
- *Joint ventures* with parents and support groups (like US Guidelines Consortium) help focus on practical common task of providing *better medical care*, instead of getting bogged down in ideological discussions.

All hands on deck?!

- www.aissg.org
- www.xy-frauen.de
- www.dsdguidelines.org
- www.isna.org