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# Confessions of a Psychologist

## unresolved dilemmas and contradictions in multi-disciplinary care for people affected by diverse sex development

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presentation trail

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# The Middlesex Clinic





# Brief history of the UCLH Middlesex Clinic

- Emergence of intersex patient advocacy/support groups, e.g., US-based Intersex Society of North America (ISNA, http://www.isna.org) and UK-based Androgen Insensitivity Syndrome Support Group (AISSG, http://www.aissg.uk) from early 1990s.

- Campaigns for changes to clinical care, including access to tailored, professional psychological support.

- From mid-1990s, a mutual endeavour by the AISSG and specialists at the then Middlesex Hospital in London → pioneering of the 1st multidisciplinary service for adult women with XY conditions. The fledgling network subsequently developed into the 'Middlesex Clinic' for intersex conditions at (merged) University College London Hospitals (UCLH).

- Marking of successful care provider/user collaboration in the 1st intersex conference in 2002 (see Creighton, Minto, Liao, Alderson, & Simmonds, 2004).

# UCLH/GOSH from circa 1999
# Paediatric, Adolescent & Adult Services

**Core clinicians:**

- Endocrinology
- Clinical Psychology
- Gynaecology
- Urology
- Nursing

**Support services:**

- Biochemistry
- Genetics
- Imaging
  - MRI
  - Ultrasound

# Middlesex Clinic, UCLH

1999 and 2000 (2 year period)

New Outpatient Referrals (by diagnosis)

Congenital Adrenal Hyperplasia (CAH) (ICD255.2)

35 new patients

XY Females (AIS and other conditions) (ICD 257.8)

87 new patients

MRKH (ICD 752.4)

21 new patients

Cloacal anomalies and other complex urology with intersex

22 new patients

Total New Outpatient Referrals = 165

# Middlesex Clinic: main diagnoses

| | KARYO TYPE | GONADS | EXT GENITAL | WOMB | PERIODS | PREGNANCY | VAGINA | BREAST DEV |
|---|---|---|---|---|---|---|---|---|
| ***CAH*** | XX | Ovaries | **Variable ambig** | Yes | Yes | Yes | **Internal** | Yes |
| ***PAIS*** | XY | Testes | **Variable ambig** | No | No | No | **Smaller than typical** | Yes |
| ***CAIS*** | XY | Testes | **Female typical** | No | No | No | **Smaller than typical** | Yes |
| ***SWYRE*** | XY | Undiffer entiated | **Female typical** | Yes | No | Yes (egg donation) | **Smaller than typical** | Yes |
| ***MRKH*** | XX | Ovaries | **Female typical** | No | No | No (surrogacy) | **Smaller than typical** | Yes |

# Criticisms from adults and user groups

- Non-consensual irrevocable cosmetic genital surgery despite an absence of long term evidence to support practice:
  - Children not methodically followed up once left paediatrics
  - Absence of evaluation from patient perspectives
- Concealment of diagnosis and treatment damaging to patients
- Medical photography poorly managed
- Absence of peer support
- Absence of professional psychological support
- Professional preoccupation with gendered outcomes

paediatric vs adult schism

# Joint LWPES/ESPE CAH Working Group 2002

*"Psychological assessment and support of the patient (with both classic and NCCAH) and his/her family should be a routine component of the comprehensive care and management of these patients. Parents and/or patients should be offered the option of age- and sex-appropriate psychologic counseling at the time of the initial diagnosis. Counseling regarding sexual function, gender role, and issues related to living with a chronic disorder should be addressed."*

# ‘Chicago Consensus Statement’ 2006

*“Psychosocial care provided by mental health staff with expertise in DSD should be an integral part of management to promote positive adaptation. This expertise can facilitate team decisions about gender assignment/reassignment, timing of surgery, and sex-hormone replacement.”* [1:e492]

# New UK guidance 2011 on the initial evaluation of a child or adolescent with a possible dsd

*"Access to psychological support during and after the diagnostic process is essential for both the affected person and their parents. In addition, any adolescent with an existing DSD who needs medical/surgical attention should be routinely offered clinical psychological support."*

*"Having a child diagnosed with a disorder of sex development can be a very traumatic time for families. It is essential that they are offered specialist psychological support, both at initial evaluation and later on once diagnosis has been confirmed."*

Professor Faisal Ahmed, chair of the guidance taskforce

# What are the obstacles to the delivery of clinical care and research compatible with the values embedded in health care psychology?

*Professional psychological input into the health care provision for people with 'intersex' conditions and later 'disorders of sex development' has been proposed since the mid-1990s. However, service delivery – its theoretical frameworks, service priorities and methods have never been coherently articulated…* Liao, 2007, p392

*Psychological interventions would invariably be influenced by an ideology of self acceptance – how does this fit with the centrality of 'corrective' medical interventions?* Liao & Boyle, 2004

*And increasingly the race to discover molecular causes for what is classified as abnormal in Medicine* Liao & Simmonds, 2013

# Professional values in (UK) Clinical Psychology

Epistemic values
- **critical** engagement with research literatures
- theoretically informed research and clinical formulation

Clinical values
- anti-pathologisation, understanding psychological problems/distress in their contexts
- evidence-based interventions
- contribution to team and organisational development
- psychological education and skills training for non-psychologists
- leadership in patient-centred psychological research

Social values
- honouring personal agency
- honouring equality and diversity
- contribution to social change via strategic action

# Difference as disease

Consensus statement-

From ‘intersex’ to ‘disorders of sex development’

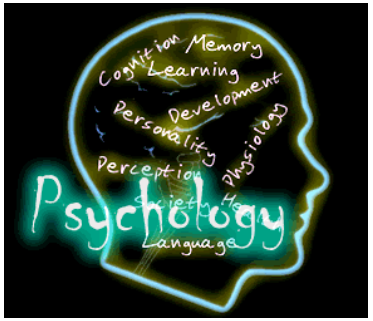
Hughes et al., 2006

- ***What does it mean in terms of societal understanding of sex, gender, bodies and identities?***
- ***What does it mean in terms of medical power?***
- ***What does it mean in terms of quality care for those so labeled, and their capacity to engage with life fully in society?***
- ***What is the role of psychologists in health care for people affected by DSD within this paradigm?***

“the continued location of life-changing decisions about intersex embodiment and subjectivity within the medical sphere”

Grabham 2007, p44

# Obstacles located within Psychology


Schism in Psychology Roen & Paterski, 2013

‘brain gender’ paradigm (see Jordan-Young, 2011; Stout et al., 2010)

versus

critical psychology (see Roen 2008)

Individual focus resulting in inadequate training in systemic solutions

Clinical psychology typically under resourced → lack of methodical analysis of the nature and extent of psychological needs to inform service design and innovative approaches.

# Obstacles located within Medicine

Unhelpful positioning of psychology in DSD services

- for window dressing (lip service to the psychosocial)
- as separate from Medicine – it's everything when Medicine has done its work (see Roen, 2008)
- as emotional repository
- as trouble shooter
- as psychometrics

  Recent flurry of 'quality of life' research is mechanistic and insufficiently nuanced for developing psychological explanations and innovative interventions. It is creating a pseudo psychology for intersex/dsd. Psychologists are failing to define the psychosocial yet again~

# Obstacles in wider society

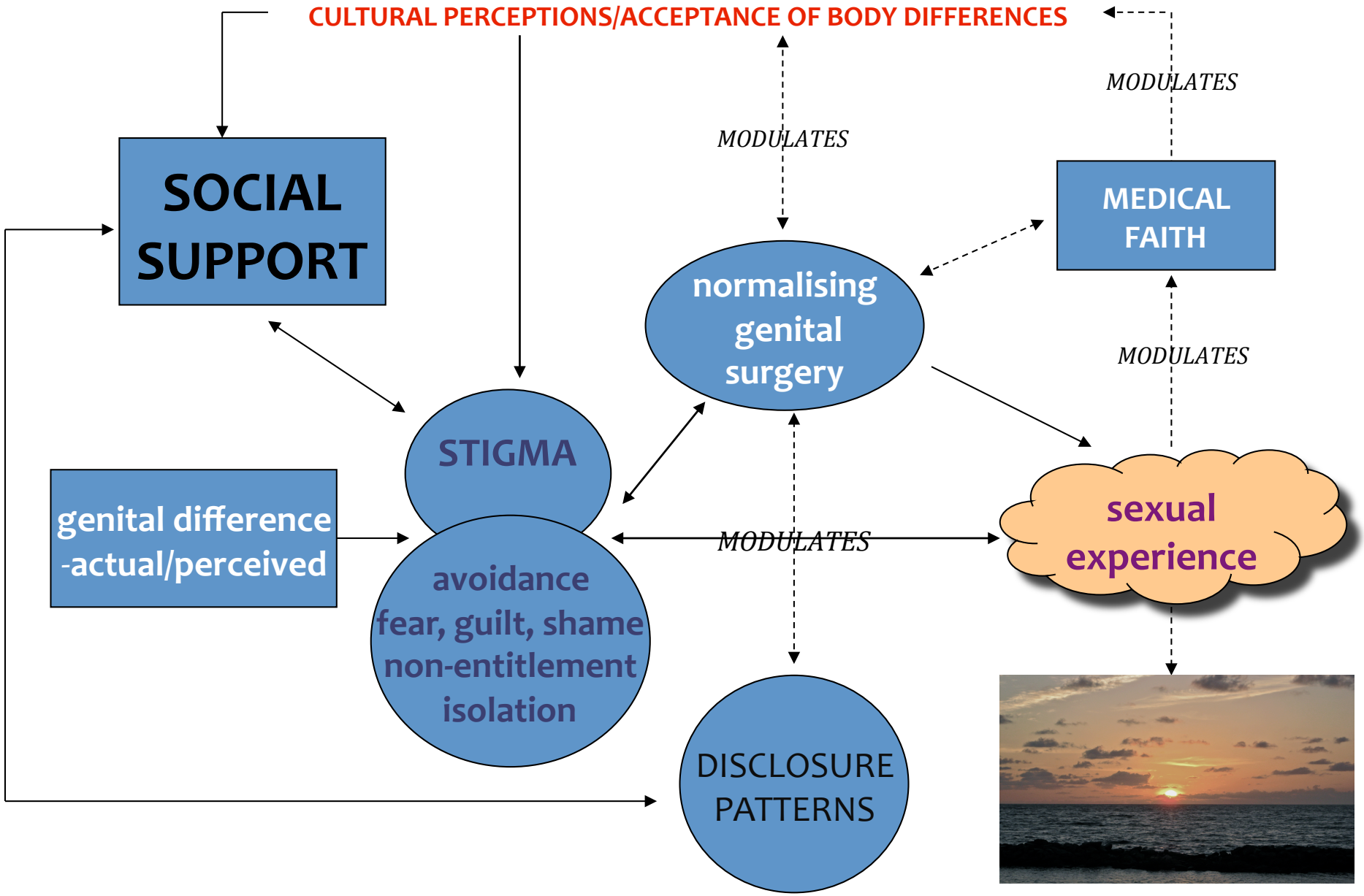
Societal understanding of sex and gender in binary terms

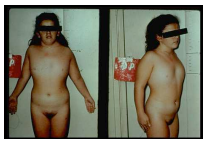
- Pressure on patients to achieve ‘normality’ – this is understandable

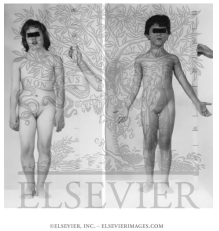
- Many patients have already decided on interventions before they attend clinic, rendering it difficult to help them develop alternative solutions

- Does normalising interventions lead to psychological well being? – as it is often assumed by doctors, especially paediatric urological surgeons

# A BIO-PSYCHO-SOCIAL FRAMEWORK FOR CONSENSUAL GENITAL SURGERY





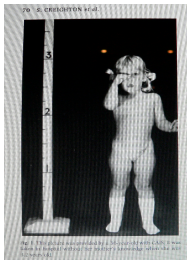


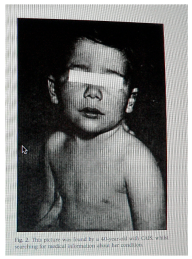

*"I remember being paraded in a lecture, they'd been discussing it and then the door opened and I was put in front of them […]"*

Liao, J Reprod Inf Psychol 2003

*"The medical profession's understandable interest in rare cases underlined my feelings of freakishness: I was introduced as an 'interesting case'."*

Anonymous, BMJ 1994



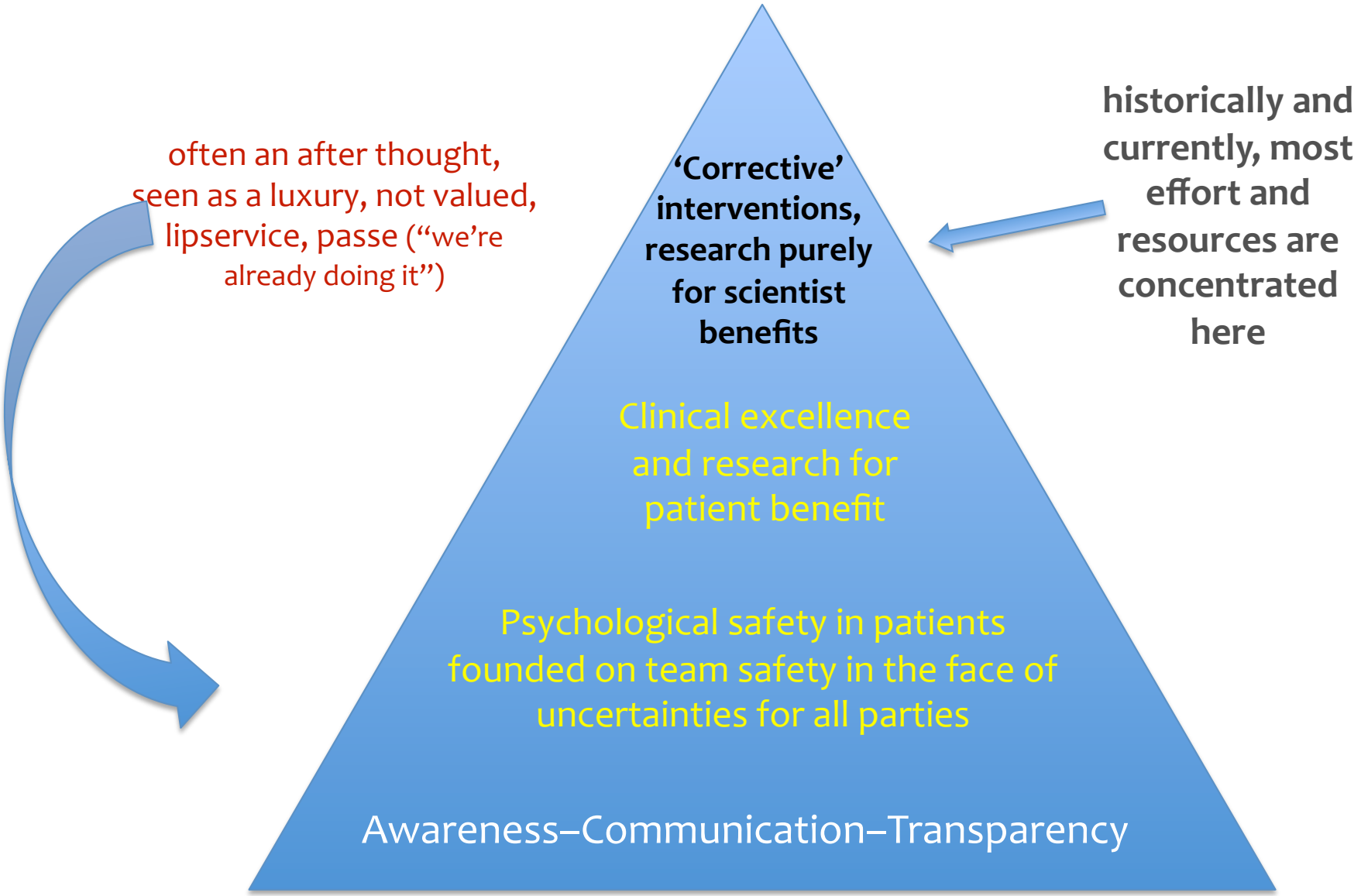


Creighton et al., BJUI 2002

**Within a difference-as-disease paradigm, surveillance/gazing is part of the package – at cellular and anatomical levels**

| | CORRECTION | **ADAPTATION** |
|---|---|---|
| VALUES | •Difference as intolerable<br>•Acceptance as unimaginable<br>•Expert-led clinical management<br>•Normal sex is heterosex | **•Difference can be tolerable**<br>**•Acceptance is possible**<br>**•Collaborative clinical care**<br>**•Challenging heteronormativity** |
| SURGERY | •Not an option<br>•Self-evident<br>•Observations obvious<br>•Intimate examinations transcends questioning | **•An option**<br>**•Subject to interrogation**<br>**•Evidence is crucial**<br>**•Observations and intimate examinations strictly protocolised**<br>**•Emotionally and cognitively informed consent** (Tamar-Mattis 2013) |
| PSYCHOLOGY | •Sooth distress<br>•Absorb problems from suboptimal care<br>•Dustbin service for 'treatment failures' | **•Work with patients (and families): increase expertise, explore meanings, co-create alternative narratives**<br>**•Psycho-sexual work: question gender performance model of sex, emphasise personal preferences**<br>**•'Holding' team: acknowledgement of moral dilemmas, increase tolerance of emotional communications**<br>**• Sharing tasks with team: optimal information delivery, research designs and interpretation of data** |
| OUTCOME | •'Normal' gendered identity<br>•'Normal' sex<br>•Absence of psychiatric morbidity | **•Perceived control of clinical care**<br>**•Optimal physical health and psychological well being**<br>**•Satisfaction with gender positioning**<br>**•SELF ACCEPTANCE** |

# moving from a corrective to an adaptation model




new paradigm informed by critical thinking

# The role of psychosocial professionals in clinical approaches for atypical sex development

Reduce polarisation and over simplification, e.g. surgery vs no surgery, normal vs abnormal

Champion and facilitate psychological safety in teams and patients

Model self awareness, contribute to an ethos of self inquiry

Reformulate research questions and improve methodology

- De-privilege brain-gender research
- Fewer psychometrics
- Improve the quantity and standard of qualitative research

**Most of all, involve colleagues to improve clinical ethos**

*"Professional documents acknowledge parental decisions regarding sex assignment and medical interventions as 'shaped by the parents' understanding of gender identity in their religious, social and cultural contexts.' My point is that decisions made by MDT members are shaped in exactly the same way. That is, doctors make decisions informed by their everyday understandings of sex, identity, and normality – understandings that they may not be aware of. This is an evidence-based claim grounded in social psychology."*

Kessler & McKenna, 1978

*"Like all good scientists, doctors and other health professionals need to be more alive to the way in which their everyday experiences, their identities and positionings, and their relationships with each other in the hierarchical and partisan social world, continually shape their inclinations and intentions vis a vis their patients."*

Iain Morland, personal communications

# a few musings…

A scientist's greatest contribution may not be the naming of genes…

A surgeon's most far reaching intervention on a patient's life may not be an operation…

A psychologist's greatest contribution to well being may never be visible, because successful championing of safety is difficult to measure…
However:-

> *"… psychological safety (the belief that the team is a safe environment for interpersonal risk-taking) is a requirement if the team is to collaborate to achieve a common goal: patient health in the sense of whole-life well-being."*

Bo Laurent, extract from unpublished MA thesis, 2008

# A long and winding road-

*"…A number of clinical documents including the Chicago consensus statement offer encouraging signs that a level of psychological care will be integrated into clinical management at major centres. However, in order to forge effective contributions informed by psychological values and principles… Significant systemic barriers have yet to be overcome."*

Liao & Simmonds, 2013

***Successful psychosocial professional networking will be a key strategy***

# EuroPSI

European Network for Psychosocial Studies in Intersex/DSD

www.europsi.org

a new multi-disciplinary professional network with user representation -
to be launched in early 2014



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