What were the consequences of reinforcing gender identity on children, adolescents and young adults with intersex conditions and/or gender dysphoria in the UK?

PhD by research in Social Science

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THE EFFECTS OF REINFORCING YOUNG PEOPLE'S GENDER IDENTITY

Looking at:

- People with gender dysphoria
- People who are intersex

Who had medical intervention

- Surgical
- Hormonal
- Psychiatric

In the UK

To learn from people's stories:

- what happened?
- were many involved?
- how were they affected?
- what are the human rights implications?
- does this still happen?
- what other ways are there to deal with this?

BACKGROUND

Medical science, in the cases of certain individuals, seeks to modify what are seen as diseased bodies in order that they conform to a model of healthy bodies. In the case of intersex children this has involved modifying and, where regarded as necessary, removing genital features that appear to the medical practitioner and parents, incongruent with the binary model of male and female sexual presentation.

This system of rendering "aberrant" bodies conformant, is what often happened to children and adolescents when manifesting gender incongruity – either because they had an intersex history or were developing a transsexual one. That entailed a process whereby gender identity was reinforced in line with other's perception of their bodies. From adolescence and into early adulthood, this process may sometimes have involved psychiatric treatment – where the object was to cure the mind of its obsession with wanting to present as a sex contrary to the corporeality of the body.

The shift towards the body in dealing with identity is broadly covered under the area of "Sociology of the Body" by a number of social theorists (Ettorre 2002; Featherstone 1991; Featherstone 2000; Giddens 1992; Giddens 1997; Shilling 1993; Weeks 1992; Weeks 2000). From these writers, it can be argued that we are moving into a society where the body is seen as a lifestyle/consumer object – something to be modified with tattoos, diets, piercing, cosmetic surgery, scarification, etc. We live in an age of body consciousness expressed in once radical politics – black consciousness, feminism.

Growing out of the awareness that identity is situated in the body as much as the mind, those with incongruities about their appearance have begun to voice their anger that they were thwarted in the physical expression of their identity before that identity had fully begun to develop. If we look at the body as being the expression of identity – the concerns about what identity is tend to diminish – and so too for the concept of 'reality'. Reality is the corporeal.

WHY RESEARCH IS IMPORTANT 1

Human Rights

When gender is reinforced it will have an effect on the development of identity, this has human rights implications.

The United Nations Declaration of Human Rights (1948)
United Nations Convention on the Rights of the Child (1989)
Crimes of hate, conspiracy of silence, Amnesty International (2000)

WHY RESEARCH IS IMPORTANT 2A

Endocrine Disruptive Chemicals – an escalating environmental problem

- Skakkebaek et al 2001 describe Testicular Dysgenesis Syndrome & possible linkage to Endocrine Disruptive Chemicals (EDC's)
- Academy of Medical Science Symposium Jan 2003
- Royal Commission on Environmental Pollution June 2003
- EU legislation & UK withdrawal of 80 Garden Chemicals from suppliers July 2003: "Ban on 80 garden sprays in poison chemicals alert" Daily Mail article, July 26 2003 "It is believed that some of the chemicals could affect sexual development in humans and wildlife"

First serious problem noticed following exposure of pregnant women between 1950's & 1970's to 'diethylstilbestrol' to avert miscarriage.

Effects of potential environmental consequences of EDC's first detailed in Theo Colborne et al "Our Stolen Futures" (1996) - Stories hit popular press in late 1990's of feminised and intersex fish

Skakkebaek et al (2001) noticed increasing incidence of what he called "Testicular Dysgenesis Syndrome" from the end of WW2 onwards in Western Europe (also noted in N.America)

WHY RESEARCH IS IMPORTANT 2B

Testicular Dysgenesis Syndrome

Most severe symptoms manifest as “intersex”, but include:

- Hypospadias
- Cryptorchidism
- Testicular Cancer
- Infertility

“The effects of endocrine disrupters are greatest during foetal development and *in utero* effects may not be manifest until adulthood… Cases of testicular dysgenesis syndrome inevitably lead to a high testicular cancer risk after puberty. Human male reproductive disorders associated with testicular dysgenesis are increasing in incidence, with 2-4% of children suffering from cryptorchidism and 6-8% of men having abnormally low sperm counts. In the US one in 125 boys are born with hypospadias, and the numbers are increasing with each decade in both Europe and the US. A possible link with endrocrine-disrupting substances must be considered, but definitive answers on a link will only be provided by carefully designed epidemiological studies.” (Royal Commission 2003) (p.233)

All these indicate that there is a significant and growing problem in western societies of genital anomaly which manifests as “intersex” at its most severe. There will be, and probably have been already, social consequences – and yet there is no data relating to the long-term effectiveness of existing models of treatment.

WHY RESEARCH IS IMPORTANT 3

If gender identity is "given"

As well as the physiological effects of pre-natal exposure to EDC's, it is becoming more widely accepted that the gender identity of people with gender dysphoria is pre-natally determined. At the meeting of the Academy of Medical Scientists, it was suggested that the effects of pre-natal exposure to EDC's may well affect individuals psychologically & behaviourally in later life. There is simply no data; so it may well be possible that foetal exposure to EDC's affects the brain, and affects the formation of neurological structures and subsequent development of gender identity.

The work of Gooren, Zhou, et al, and Prof. Diamond, and others are set against the 'popular' position that identity is formed in early infancy - brains appear to be wired for gender pre-natally.

This opens up the question of what happens on trying to alter a given gender identity – or reinforce the wrong one – during childhood.

WHY RESEARCH IS IMPORTANT 4

Third sex, third gender and intermediate states

Intersex activists have tried to call a halt to what they call inappropriate “Infant Genital Mutilation” (IGM). They argue that this needs to be delayed where possible until the children can make their own decisions – because some are not happy with the cosmetic result, or the identity assigned.

Magnus Hirschfeld wrote in the 1930’s

> “in absolute, pure cultures there are not only two sexes, but also intermediaries, whom people have also, not without justification, termed the third sex” (Homosexuality of the Male and Female, trans 1991)

Could transitional states be helpful? Some intersex people argue that they would. By looking at the experiences of those who do not “fit” the accepted norms of the binary gender system, we can begin to ask whether such states might be one way of approaching this paradox.

REVIEW

This Research Project

This Approach to the Subject is a multi-disciplinary perspective which gives a voice to those affected.

- There has been little research done on the long-term consequences of intervention, or on the model of gender we use, on people's lives.
- There does not appear to have been work on this that includes social-anthropology, culture, gender & queer studies in the UK
- People concerned rarely get the opportunity to talk of experiences other than in the press or on talk-shows, which usually have an "angle".

By way of literary review I am covering:

- "Intermediate States", etc., originally associated with homosexuality, from Karl Ulrichs and Edward Carpenter.
- The "coming out" narratives of lesbians and gay men
- Accounts of survivors of child sexual abuse, as well as other "survivors".
- Ethnographic accounts of the Xanith, Hijra & "Berdache" which indicate that third-gender alternatives tend more to reinforce gender stereotypes.

Michel Foucault, who contributed much to the discussion about social control, discipline and human sexuality at the end of the last century.

METHODS

Methodology

- qualitative study
- autobiographical techniques
- analysis of oral histories
- interviews with professionals
- grounded theory

Grounded Theory

- Exploration
- Data Collection
- Analysis
- Theory Development

Autobiography

Life story, narrative, is a tried and established format historically – St. Augustine, Jean-Jacques Rousseau, Alice Walker, etc.

Within social anthropology, it is often the only way to get at data (survivor narratives). In this case, hospitals or their records are closed, patients records are not conserved – often memory is all that is left.

PEOPLE AND EXPERIENCE

People's Stories

Asking people having had experiences of appropriate types of interventions for their autobiographies.

First an oral or written history, or testimony, relating to the relevant experiences – and any subsequent effects. This to be supplemented by follow-up interview(s) – structured and then informal if necessary

Research Participants

Twenty-five to thirty people having had experience of medical intervention related to their gender identity or genital/gonadal appearance or function between the ages of 5 & 25 years old.

Taken from FtM TS, MtF TS, lesbian, gay men, intersex people, or heterosexuals (acknowledging there will be overlaps between these 'categories')

Professionals

Asking professionals in the field through confidential interviews what they have done in the past and what happens now.

Asking activists and advocates what they see as having happened and as happening now.

CALL FOR PARTICIPANTS

Participation

- If you feel you had relevant experience and would like to participate…
- If you work or are active in this area…
- If you have clients that might be interested in participating…

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