The Transexual Person is my Neighbour:

Pastoral Guidelines for Christian Clergy, Pastors and Congregations
by Rev Dr Christina Beardsley

APPENDIX: INTERSEX

By Michelle O'Brien

There are a range of intersex conditions, which are usually taken to be different from transsexuality. Medical views are usually that intersex is a set of physiological issues, and gender issues are rare amongst intersex people; many intersex advocacy groups stress this as well. Some experts (such as Professor Milton Diamond) consider transsexuality to be a form of intersex, and a growing number of transsexual people agree with this. The best way to find out information on specific intersex conditions is to search for condition-specific support sites on the internet; these tend to focus on the medical aspects of these conditions, and not the social, gender or psycho-sexual issues.

It is difficult to summarise or categorise how different intersex conditions present themselves because one individual's experience may vary from another person with the same condition. Intersex Society of North America (ISNA: www.isna.org), a US advocacy group, tends to follow the medical model, to the extent that it endorses viewing intersex as disease by using the nosology 'Disorder of Sex Development', focussing on the physical aspects and seeking demarcation from those with 'Gender Identity Disorder'. Other groups, such as Organisation Intersex International (www.intersexualite.org), which reject the terminology of disorder, are less amenable to categorisation; like Milton Diamond they regard intersex as a form of sex variation covering a range of issues which may affect gender as well as physical aspects of sexual development and other more serious health-issues.

Androgen Insensitivity Syndrome features among people with XY chromosomes, and the degree of intersex can vary between Partial (PAIS: usually male phenotype), Mild (MAIS: can be mixed phenotype), and Complete (CAIS: usually female phenotype). Many people with AIS are assigned female and have no gender identity issues; some people with AIS are assigned male, and have no gender issues, but are more concerned with assistance in maintaining erections and being able to father children; there are people with AIS who are assigned male who would have preferred a female assignment. 5 alpha-reductase is an XY-chromosome phenomenon and presents similarly to AIS; usually people are assigned female, and there have been incidents of people transitioning to male after adolescence; there are individuals who were assigned male who would have preferred to have been assigned as female.

People with Congenital Adrenal Hyperplasia (CAH) usually have XX chromosomes; the action of the adrenal gland producing too much cortisol can be life-threatening and can entail virilisation. Some people with XY chromosomes can have a form of CAH, but the effect is opposite to that among those with XX chromosomes; they can be under-virilised and assigned male, and a few of these may have gender or fertility issues later in life. Some people are XX, develop a female phenotype, but have a late onset of CAH (LOCAH), and start to virilise in adulthood. The issues for many of these people are not about sexual assignment or gender identity, but survival, because of the stress placed upon the body by the way the adrenal glands function; salt-wasting and adrenal crises can be life-threatening.

XX/XY, or mosaicism, is what used to be called 'true-hermaphroditism'. Individuals have a mixture of XX and XY chromosomes in the body, and can present phenotypically as a mixture of both sexes. These people are rare, and what are usually referred to as 'hermaphrodites'; more recently their bodies have become fetishised on certain internet sites.

Some people have a missing sex chromosome; represented as XO this is known as Turner's Syndrome. They appear female at birth, but because there are no primary sexual organs secondary sexual development does not occur at adolescence.

People with Klinefelter's Syndrome are categorised as such because they have extra X chromosome(s), usually represented as XXY. They appear male at birth, but the lack of testosterone means female fat distribution and breast development may occur at adolescence. Most children are assigned male, and adults tend to live in society as men (usually infertile); some do have a female gender identity and transition to live as women.

In addition to those listed above, usually regarded as naturally occurring intersex conditions, hormonal imbalance in pregnancy from exposure to external agents can cause intersex in the developing foetus; this is referred to as Progestin Induced Virilisation (PIV). In 1960s and 1970s some women were given progestin to help with problems in pregnancy; when the foetus had XX chromosomes, the result could be the birth of a virilised child. Such children were often subject to 'corrective' surgery, some assigned male, some have rejected their assignment in later life; there are those who regret the surgeries as a child. A similar situation has been put forward for people with XY chromosomes exposed to oestrogens during pregnancy, either in the form of diethylstilbestrol (DES) or environmental endocrine disruptive chemicals (EDC's). This has been hard to prove, but is increasingly being adopted as a cause among people with intersex-like symptoms but who have no clear intersex condition that they can be diagnosed with; it is suggested as a cause for male infertility, genital malformation, testicular cancer, and even transsexuality. As with PIV, surgeries may have been seen as being required to 'correct' genital anomalies, and individuals have later rejected their original sex-assignment.

Most intersex people are not concerned about the appropriateness of their sex assignment, but those who experienced early childhood surgeries do have issues about those surgeries carried out to ‘correct’ genital anomalies and the legacy that leaves them with. Not all intersex people did experience such surgeries, however, and it is becoming increasingly the case that doctors in the UK will try to avoid surgical intervention whenever possible.

There is limited information about the incidence of these conditions; what there is tends to be gleaned from various studies which give percentages of samples that are then extrapolated nationally. I am wary of these estimated figures as those published are usually very conservative whilst some intersex advocates are more generous. The numbers concerned are usually influenced by the person’s definition of what is genuinely intersex; some experts do not count CAH, some do not count Klinefelter’s. Some experts give a very conservative estimate based only on the incidence of mosaicism (which is extremely rare); others will confine themselves to those who have identifiable causes; others will include those who have an intersex presentation with no chromosomal cause, but some unknown hormonal factors that can be traced back to early childhood or prenatal factors. The broader view places estimates as high as 2% of the population; the narrow view is that intersex is very rare. Many people do not know that they are intersex, as this was kept from people for many years.

Research that has been carried out looking at the figures from a number of historic studies suggests that the numbers of intersex people who go on to reject their birth-assignment and change sex is around 6-7%, a proportion that is far higher than for the numbers of transsexual people in the general population. Intersex is more common than transsexuality, but less public.