



Intersex Article 5: Communities

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When people discover that they have intersex conditions or first realise that there are others out there in similar situations who're willing to talk about it, often their first concern is how to contact intersex communities. In some rare cases, due to the circumstances of their birth, intersex people are already part of intersex communities living within mainstream society. Either way, communities play an important role in providing support and information and helping people to make their voices heard. They can also provide useful resources for the parents of intersex babies.

Most intersex communities are condition specific - that is, all of their members share the same intersex condition. This can be very useful when it comes to sharing support and advice and collecting information, but it does mean that some groups are quite small and, while they may thrive in an online environment, it's difficult for members to find local support. This means that some intersex people can still feel very isolated in society at large, even if they are members of online or correspondence communities.

Over the past fifteen years, umbrella organisations have emerged to bring together people with different types of intersex condition. The largest and most famous of these is ISNA, the Intersex Society of North America. Consequently, it has led the debate on many of the political issues which face intersex people. It provides an impressive array of resources including lots of medical information, and it has allied itself with several respected medical professionals whose aim is to improve the way intersex people are treated by the medical establishment.

In the UK, The United Kingdom Intersex Association (UKIA) acts as a campaigning group on behalf of intersex people with all kinds of different conditions. It is unable to provide medical information but can refer people to appropriate support groups and specialists. It is primarily concerned with education, both for the public and for intersex people themselves.

There are several online communities where intersex people can meet and talk. Some of these are exclusively for intersex people whilst others also welcome their friends, partners and family members. There are groups which are only for intersex people who have received medical treatment (usually including surgery) for their condition, there are groups which limit membership to people with one of several named conditions, and there are groups which are open to people with borderline conditions.

The intersex community often breaks down into two groups: those who have undergone surgery without their consent, and those who have not. Sometimes people in the latter group complain that they feel excluded or are not considered 'true' intersex people, but there are still several groups out there which aim to cater to their needs. People in the former group share a traumatic experience which it's difficult for other people (even people born with similar anatomies) to relate to, so they need a different kind of support.

In some parts of the world, where there are high rates on intersex births, intersex people form a natural part of the wider community and are able to live openly within a society which respects and understands them. This is true of the guevedoche people of the Dominican Republic and the kwolu-aatmwol people of Papua New Guinea. Because of the way they are affected by their 5-alpha reductase deficiency, these people normally live as girls until puberty, after which point they start living as men. Their societies do not give them special roles because they are intersex (though in the past they were sometimes believed to have magical powers), but neither do they stigmatise them.

In eastern France, where a large number of children were born with intersex conditions after exposure to radioactivity from the Chernobyl disaster, a community of intersex people is beginning to form spontaneously. This will be the first modern instance of wider society suddenly having to get used to the presence of a significant number of people who are open about their intersex conditions. Organisations within this community are campaigning for greater openness from the French government.

For some people, living with an intersex condition is an extremely private matter, but even those people may find intersex communities useful. It is possible to communicate with them anonymously and confidentially. People are also creating new intersex social and campaigning groups all the time in order to cater for the different needs emerging amongst the intersex population. Thanks to groups like these, intersex people no longer need to feel isolated or feel that nobody understands what they have had to go through.