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Ways to Happiness with an Intersex (DSD) Diagnosis

Barbara Thomas
XY-Frauen (www.xy-frauen.de)
AISSG UK (www.aissg.org)

Parents with an infant or child with a Disorder of Sex Development are sometimes in danger of seeing a DSD as an insurmountable obstacle to happiness.

Those affected by a DSD diagnosis...

- Are confronted with many obstacles throughout their lives, both by the challenges of the diagnosis and by the behaviour and reactions of others.
- These obstacles can consume so much mental and emotional energy that it is hard for them to get on with more important life tasks. Lives and talents are wasted.

What specific challenges do we face? How can they be dealt with positively?

- Parents who feel ashamed or guilty
- Being different
- Secrecy
- Being lied to
- Isolation
- Childlessness
- Doubts about sexual attractiveness, marriageability etc.
- Possibly, unhappiness with assigned gender, or surgery which cannot be reversed

Parents who feel ashamed

- The bodies which human beings are born with are not what anyone has chosen or achieved. DNA is not earned.
- The development of the uro-genital tract is so complex. Complex processes do not always go according to plan.
- A DSD diagnosis should not be pathologized!
- Every human life is a gift, of infinite worth.
- Guilt feelings about one's child's DSD are neither justified nor helpful.
- Parents may need psychological help to understand and accept this.

Being different

- All human beings are different, all are unique.
- Variation should not be seen as a threat.
- Always remember the huge variation both in genital appearance and gender identity in all human beings.

Secrecy

- Secrecy is poisonous, it gives the message that there is something bad which must be hidden.
- Secrecy runs away from the truth - it is cowardly.
- Secrecy destroys trust.
- „We are as sick as our secrets.“ (Alcoholics Anonymous)

Being lied to by parents and medical professionals

- Lies destroy human relationships.
- One cannot build a future on lies.
- People are not stupid. Most of us who were lied to by parents and doctors knew or sensed they were lying to us.
- Facing the truth about reality, about who we are, may not be easy, but is the only healthy way.
- Do we want to spend our lives trying to be someone we are not and can never be?

Isolation

- Isolation is harmful and unnecessary. You are not alone!
- 1 in 2,000 births is a DSD birth (i.e. 35,000 Turkish citizens?!)
- Meeting others with a similar diagnosis gives a feeling of normalcy and is the single most healing experience on the way to accepting one's diagnosis.

Role of the support group

- Automatic understanding by people who have „been there.“
- Parents support and advise each other.
- Affected adults can support and accompany the younger generation.
- DSD children benefit from a feeling of normality early on in life from knowing each other.

Childlessness

- To be childless is a source of great sadness.
- 10% of all couples worldwide have to learn to accept this fate, but knowing from the outset of a relationship is also an advantage.

- "There are no short cuts around the personal grieving process, working through our despair is not something that can be avoided." (Richard Rohr)
- Is a human life only fruitful in the biological sense?

Doubts about sexual attractiveness

- All honest human beings have doubts about their sexual attractiveness.
- Is sexuality about performance or expressing love?
- People with DSDs may need professional help to be able to function sexually. It is easiest to talk about this intimate subject with others who are affected.

Marriageability, finding a partner etc.

- Many adults with a DSD diagnosis are happily married, or are in stable long-term relationships.
- Some adopt children.

Unhappiness with assigned gender, or irreversible surgery

- It is hard to describe the immensity of distress of the affected adult who feels that their body has been mutilated by irreversible childhood surgery.
- Some parent-child relationships are destroyed for ever as a result of parents having consented to irreversible surgery on their children.
- The first priority should be preservation of tissue and the integrity of the body, *whenever possible*.
- Especially if there are doubts about adult gender identity outcome, *try* to avoid or postpone irreversible cosmetic surgery (or surgery which causes infertility) until informed consent can be obtained.

Waiting with surgery

- Time is in the patient's favour.
- Better techniques and more knowledge about long-term outcome will be available ten years later.
- Preserving tissue keeps options open for the future.
- Patient consent and motivation protects the surgeon.
- Litigation only makes lawyers happy.

When considering surgery

- Make sure that parents who have to make difficult decisions about surgery are fully and realistically informed of the advantages and disadvantages both of childhood surgery and of waiting with surgery till adulthood.
- The patient's long-term well-being is the most important factor in all management decisions, especially surgery. Surgery on children is not an appropriate way to deal with parents' distress.
- What *else* can medical professionals do to increase the chances of their intersex patients leading happy, fulfilled lives?

Give the right messages

- The first message parents of children with a DSD should be given is that they have a beautiful, healthy child.
- FULL STOP, END OF PARAGRAPH.
- Children with DSD must be given the feeling that they have infinite value, that their life is a gift.
- Emphasize that the special challenges of a DSD diagnosis can be coped with.

Focus on their potential

- Give parents sufficient time and support to fully understand and accept the truth of the diagnosis, using explanations that are simple and value-neutral.
- Do not use terminology which is hurtful or discriminatory or which pathologizes the phenomenon. (Chicago consensus)
- Emphasize to parents that they are part of a worldwide community of parents who share a special challenge, that they are not alone.
- Give patients and their parents the opportunity to help each other by encouraging support groups.
- Do not subject children and teenagers to medical photography, or display them to students. This causes deep, lifelong trauma.
- Keep intimate examinations to an absolute minimum, and make sure that the patient's consent is a result of earned trust, not of fear of displeasing one's doctor.

Finally

- Having a DSD brings challenges that can be coped with. It is not the end of the world.
- Do not allow a DSD to stand in the way of a person fulfilling their human potential and making a full contribution to society.
- There is no reason why a person with DSD should not find happiness.
- May you have many DSD patients who, at the end of their lives, look back on their medical treatment with gratitude!

Further information

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