Working together in placing the long term interests of the child at the heart of the DSD Evaluation

Ellie Magritte, dsdfamilies.org, info@dsdfamilies.org

Presented at the ***Working Party on DSD Evaluation***, Annecy, 16 March 2012

---

*" …Finally, there must always be room for the atypically sexed child to imagine and to **become**, of their own accord, rather than to simply respond to what has already been imagined for them." (Katrina Roen (*))*

I am the mum of three great kids, all with their own little character traits that can make being a mum both rewarding and exhausting. My eldest daughter has just turned 10 and was diagnosed at birth with Partial Androgen Insensitivity Syndrome. I am also the administrator of a new support and information resource for families of children and for teens with a DSD, called dsdfamilies.org.

I had the pleasure of meeting some of you at the ISHID conference in London back in September 2011. I was glad of course to be told of the positive feedback following the presentation I gave there. But what few of you will know is that I spent most of the morning of my presentation very distressed, and sobbing, frankly.

No, it wasn't Sarah Creighton's matter-of-fact analysis of long term outcomes of early surgery that caused it…but it was a remark made by the American psychologist David Sandberg.

He talked about how parents shouldn't be put in the position of making decisions immediately after the birth of their child. He said, and I quote: 'Parents are a mess.'

Perhaps I would not have chosen that blunt word 'mess' myself, but his words did two things: firstly, it was like someone held a mirror in front of me, forcing me to look at this parent who, if truth be told, still struggles with everything that happened in the weeks, months and years after the birth of her beautiful first child.

Secondly however, his words also crystallised a nagging feeling I've been having since arriving at that conference: everyone seemed to be talking about technicalities and techniques: what do you do and how do you do it?

It was so very different from what I wanted to hear you talk about.

In an email sent by Pierre Mouriquand about this conference, he stated his aspiration that each participant should list the most important questions.

I am afraid we parents have rather a lot of questions:

(*) Roen, Katrina, 2009, Clinical Intervention and Embodied Subjectivity: Atypically Sexed Children and their Parents, in 'Critical Intersex', Morgan Holmes (ed.), Ashgate Press 2009

How do you cope with having to assign a gender of rearing for your own child?

How do you tell well-wishers that you don't know whether your baby is a boy or a girl?

How do we deal with having to make fundamental and sometimes irreversible decisions about the care of our children if the doctors who inform us –often the only ones we discuss care and interventions with - are also those to whom we have to give informed consent in acting on those decisions?

What happens to parents and their affected child following the initial 'evaluation', when we leave the hospital? Or when we leave the DSD clinic?

Which expert provides continuity of care during those long periods when we do not see the MDT, but during which the questions on what to do, what to say, how to deal with this or that… keep coming?

How do you ask the school to allow your young son to use private changing facilities and toilets, so he will not run the risk of being ridiculed and bullied?

How and when do you tell your daughter that she cannot grow babies in her tummy?

How do you prepare your child for a genital exam?

How do you share information about their condition, and instil a sense of privacy without attaching a sense of 'wrong' or 'shame'?

How do you explain scar-tissue?

Where can your adolescent daughter go to talk about sex when her body is different from her teenage friends?

How do you raise confident and happy kids with a DSD?

How do you place building self-esteem, a positive body-image and resilience at the heart of their care?

How do you help your daughter understand that having good sex is not the same as having a typical sex anatomy?

My questions, my dilemmas, are probably very different from yours.

When honing in on evaluation…

Shouldn't the key questions include how to place the long term interest of the child at the heart of that evaluation, and who decides what that long term interest is anyway?

Surely any update on *evaluation* has to be holistic, and include all dimensions of care, not focus in on surgery above all else.

How we *describe* genitalia (avoiding outdated and insensitive language);

Whether and how we discuss long term outcomes of early surgery with families (both for girls and for boys);

Whether and how we support the family through and following a sex assignment process;

Whether and how we offer families a vision of 'normality through acceptance' rather than via early surgery …

all these things affect the outcome of any evaluation, and indeed, impact centrally on the decision-making process as to whether surgery is the right choice for a family…

Surgery may be, and often is, a choice that parents make, but whether they are adequately supported to make that choice with the right information –and in the right frame of mind- is still, too often questionable.

I am not here to give you any answers, but to work with you in helping families feel as supported and as informed as possible.

I can tell you about two things:

The first one is a parental experience of gender assignment – a narrative that has been hidden for far too long it seems. I was quite shaken when a few months ago a senior endocrinologist told me how shocked he had been 'to read recent research about parental distress at the time of a gender assignment, and how indeed some parents suffered from Post-Traumatic Stress Disorder years afterwards.' How I wish I had the presence of mind to say 'how can you not have known this?'

The second thing I can tell you is about raising a child with genital difference.

First, a brief recap of my first child's birth:

My daughter was born following an emergency caesarean; everyone in the delivery room congratulated us on our beautiful daughter. Some 12 hours later, after telling all our friends and family our good news, a junior doctor told me –without my husband being there- that her swollen labia might have testes in them.

A few phone calls later, my mother confirmed to me that at least two members of my family had been diagnosed with what was then called 'testicular feminisation'.

The family knowingly took the chance of not telling me about the hereditary pattern of the mutation, therefore taking away from me the opportunity, *and my right*, to fully prepare and inform myself.

It took another five long days before we were introduced to the clinical experts, a paediatric endocrinologist and a surgeon.
During these first five days in the maternity hospital one consultant would contradict the other leaving us in total despair as to what was going on with our child.

During this time we avoided friends and phone calls, and Internet research did nothing to give us hope about the future our daughter would have or to help us understand the situation we were in and what we were to expect.

On day six, at our first meeting, the surgeon comfortingly put his hand on my husband‘s shoulder. That small act of human kindness still stands out.

I did not want this doctor to go away, but I did not understand why he was there: there was nothing wrong with my child, she was perfectly healthy. She had xy chromosomes, but I knew for sure you could not cut the y chromosomes away – what did *a surgeon* want to do with her?
I still wish he had introduced himself as ‘a urologist ‘– perhaps then I would have understood his perspective.

The other doctor was an ‘endocrinologist’. He too was very friendly, very soft-spoken and empathetic; but I did not have a clue what he did, what he measured, what he looked at – how he was involved in the care of my child.

We wanted to know how our daughter was going to cope psychologically with having xy chromosomes.
They told us that first our baby had to go through a gender assignment process.

A few months ago I was asked by a clinician, a urologist, what happened at my daughter’s birth. I think this was the first time anyone had actually asked me, the first time I spoke about this out loud.

And so I could not stop crying as I was trying to explain how I experienced the gender assignment process: that it feels that the baby you had might have to pass away and that instead there might be this new baby, with a different sex, whom you'd learn to love too, but still, the child you had would be gone forever.

And the answer from this doctor: ‘We don’t need five urologists on our team, we need five psychologists’.

Some twelve days after her birth, we agreed with the recommendation to raise our baby as a girl. We were given a final piece of advice ‘don’t lie to her, never lie’; and we never have.

A gender assignment process is always going to be traumatic; but how we, you and support resources together, support parents at that time can make a fundamental difference
1. to the decisions that are made during and following the DSD evaluation and
2. to the ability of parents to adapt and accept the diagnosis.

I was recently introduced to a mum of three girls, with the eldest two girls having CAH. I told this mum about me coming to talk to you here and asked her if there was anything I could raise on her behalf. A few days later, she sent me the following:

For my two girls who have enlargement of the genitalia as a result of a medical condition (CAH) I believe that there are two key factors in helping them to come to terms with their condition. One is that their parents accept and are comfortable with the physical effects of their condition and the other is that the emphasis of their condition is not placed on these obvious physical effects.

It is very traumatic for parents to be told that there is uncertainty over the sex of their child and that a very private part of their body is 'different'. Surgery in childhood to cosmetically reduce the obvious physical effects of differences in genitalia may help parents to feel that their child is more 'normalised' and therefore help alleviate some of the anxiety and stress. However, this alone does not help parents to come to terms with, deal with the challenges and fully accept a complex and private condition and to know how best to support their child. I believe that if parents continue to struggle to accept the condition the child will be very aware of this and will be negatively affected.

I want all my 3 daughters to grow up to be happy and confident with whom they are. This is not dependent on them having the 'perfect' bodies, if that were the case we would all be miserable!

CAH is a very complex condition and enlargement of the clitoris is only one way that females are affected. However, as it is an obvious physical effect a lot of emphasis can too often be placed on it. It is only at 9 1/2 years old, in the run-up to swimming classes at school, that I have made my eldest daughter aware that her medical condition has affected the appearance of her genitalia, despite having a younger sister who is not affected. In fact it took 4 years before either of my girls with CAH noticed that their genitalia were different than their younger sister's. With the wonderful wisdom of a child my eldest daughter responded to her sister's query about this that: "We are all different!"

This brings us to the second part of the presentation: how to help parents imagine and understand that deferring surgery is <u>a realistic</u> option?

New parents are afraid, and instinctively want to 'protect' their child and equate that to surgery.

But it is my sense that this has often to do with not knowing how to deal with practical issues: how to deal with babysitters, and how to deal with nurseries, what happens if someone offers to change your baby, or when you are on the beach? And how to cope with those swimming classes….?

With all the knowledge and evidence we have, surgery should no longer be a treatment to pre-empt bullying, and certainly not a treatment to alleviate parental anxiety, without at least trying first to build better support and management strategies.

I want to share some of these with you, as it is to you that new parents will look for advice and instruction.

First however, I would like to make two comments between parentheses:

1. You may have noticed that I avoid the terms ‘genital ambiguity’ or ‘ambiguous genitalia’, which I think are very unhelpful, and suggests ‘wrongness’, ‘something in-between’, which really only plays into the ‘exceptionalism’ that surrounds these conditions and helps to produce secrecy and isolation. I use the term ‘genital difference’.

2. On dsdfamilies.org , you can find a collection of stories called A`s story`. These describe the experiences of A , a 5 year old boy whose gender was reassigned following his adoption and lives with genital difference. Last week, his mum went to talk to the principal of his school to discuss the forthcoming swimming classes.

Rather than asking for ‘protecting’ her son from exposure, she decided to recruit and empower all his minders to reinforce the message -if needed- ‘that A does not look like a girl, he looks like A and that is good. We like A just as he is.’

It is a wonderful example of the progressiveness, the cleverness and the boldness that we need in this debate about raising kids with genital difference.

Raising an XY boy with *greater genital difference*, is a different scenario to raising an XY girl with a *lesser genital difference* – there is a fine line between protecting and empowering.

(Language)

I notice how some families are uncomfortable to talk about genitals. I borrowed an innocent little word from a francophone friend for female genitals – we call it a mimi. My girls have mimies and my son has a willie. When you can talk about mimies and willies openly, it is not threatening. ‘Your mimi is a bit different’ – that is not scary, not to a child, and not to the parent who has to tell it.

Mimies and willies are private – that is a message that my daughter has heard from a very young age onwards, and I continue to use that very same message now also to her brother and sister.

(Changing, beach)

I recently read an unpublished interview in which parents argued against their doctors recommendations in favour of surgery ‘because it made changing one’s child on the beach so much easier’.

When you are a new parent, you probably have only seen the baby clothes and the pram sections…You probably don't know that there are wonderful Dora the Explorer or Dinosaur hoodie towels that all little kids love to have on the beach – it is *those towels* that make changing on the beach so much easier…

(Changing, babysitters)

My advice to parents who consider surgery in case 'a babysitter' might notice would be something like this:

Take a few months to recover from childbirth (I am not the only parent who was far too tired for months to simply consider going out!), get your feet back on the ground, and take some time to adapt to the diagnosis. Only then are you in a position to consider properly all the options for your child's care.

During that time you learn so much about the diagnosis; it becomes less overpowering and less all-consuming and less frightening. You will have experienced a few awkward situations, like a friend wanting to change your baby's nappy… Again, there are many strategies: you can say 'Oh, I really want to change her nappy myself- it is special bonding time for us' or a firmer 'You don't want to do that – each time we remove the nappy she does something; I'll quickly go and do it myself, but thanks.'

Or, take a leaf from my friend Maggie's book and tackle it head-on. She says: 'I had good experiences with just mentioning it at the end of the typical "this is what you need to know" conversation with babysitters (and kindergarten!). I would say: "Oh, and if you are helping him in the bathroom (or putting a nappy on for bed), you may notice that his genitals look a little different. Don't be worried, this is how he was born, and he is healthy and fine." I have had no questions or strangeness from these caregivers.'

(Nurseries)

The mum of a CAIS baby recently shared with me that her 10 month old daughter's labia are very swollen, and despite the reassurances of her medical team, she is worried that people at the nursery her daughter will be starting soon will notice.

Her email reminded me of my own concerns about how other people would view my daughter's genitals. I wrote back and shared Maggie's approach : 'If someone were to say that her labia look a bit swollen, just say that she was born that way, she has been checked out and she is perfectly healthy. Full stop. I do understand how you feel though - I remember looking over the shoulders of other mums in the John Lewis baby changing rooms trying to see how their girls look like and whether mine was very different.'

Next time I write I'll tell her how after changing nurseries, I spent my daughter's first day at her new nursery PETRIFIED. By that time my daughter's clitoris had become more pronounced and with a urogenital sinus one could clearly see 'difference'. When I picked her up I *panicked and blurted out* to the young member of staff who handed my daughter to me 'she looks a bit different doesn't she'. The young woman,

did not have clue what I was talking about. The majority of staff at nurseries are young people who have very little experience in 'life' – I felt so silly for having been scared of this young woman, who has totally different things on her mind that what my girl's genitals look like.

The mum of a little girl with Ovotestes told me about the support she *receives* from the nursery: 'The director of my daughter's nursery could not have been more supportive, saying 'don't worry – all children are different', and they have always helped me and my husband to treat the issue calmly and with 'normality' – but she adds: It is not always easy, living in a small village.

Caring for a child with genital difference means you are always on alert, but once you get used to it, it is not so difficult.

What is difficult is having to do it amid the isolation that can come all too easily from our children's diagnosis, and this is where we parents need your help, in stimulating contact between affected families, in helping us share these experiences, with each other, with you and with the many parents who are too afraid to reach out to each other.

What is also difficult is that sometimes we don't really know how to care for genitals that are different. When my daughter was around 4, and we were in-between medical teams living in the UK, I was worried about some white discharge. Who was I to ask? I ended up emailing Piet Hoebeke, who I did not know as a doctor, but I had read some comments by him and hoped he would help. And he did; he replied very quickly, and my family will always remain grateful for that. And as he wrote, the discharge is nothing abnormal, just needs a regular wash.

But when you have no-one to ask, it can turn 'nothing abnormal' into something insurmountable, something scary and something that causes anxiety.

Are there tricky situations: yes.

When early January, after the first day back at school, my daughter told me 'this term we are having swimming mummy; it's tomorrow', my heart sank, and I thought ' Oh no, not again, I thought we did the swimming in year 4'…

The rest of the afternoon I was really concerned about what I should do: I don't want to make her difference a bigger thing than it is, but equally, I need to 'protect' her, or as I have come to see it 'empower her to protect herself'.

So that evening in the car on the way to the Scouts, I said to her 'So, you are having swimming tomorrow?'

Yeah, she says.

Do you remember what I told you about keeping private bits private?

Yeah mum, and she rolls her eyes.

OK sweetheart, I said, sometimes I don't know if you remember the stuff I tell you, but if you do remember that is fine.

A minute later, I dropped her off, and that was it.

Thank you.

A's Story: Meeting the Principal (March 2012)
By Laurie, co-administrator of dsdfamilies.org, info@dsdfamilies.org

It took a lot of courage to do this, and I'm not sure it will be something other parents feel they could do, but I know that hiding something as if it's shameful is more damaging than admitting it's there and getting on with it.

So, on approaching our principal who is also the Junior Infants teacher (my son's class), I asked for a meeting regarding A's swimming lessons. I start with the attitude that A cannot be treated any differently than any other child, especially his sister. Anuj just completed swimming lessons with the school today and A's class will start up in May.

As you know, A has PAIS. It is on his school record as a medical condition, and his teacher/the principal, knows about the condition. (as reference for this explanation, and so people know what A's condition is, I'm adding this next sentence) A's genitals look like a girl's genitals but with a big clitoris. You cannot see his testes, though descended, because the way he stands, they are hidden by his thighs. At first glance, you would assume he's a girl.

So, my first rule: do not treat him differently, had to be addressed when the principal asked that I come along to help A dress. I told him that I could not and would not do this. First of all, I'd have to explain why Anuj didn't get mommy to come along (that's not fair!), and secondly, I'd have to explain why A gets special treatment the other kids don't get (other mommies are not allowed to come along).

Secondly, I had to explain to the teacher that he could not be treated differently by the teachers, or the other supervisors (swimming instructors in the pool facility), but that as boys often think it's funny to yank swim trunks down, or A might jump up suddenly out of the water, which could accidentally pull his shorts off of him. So, each person involved in A's minding is asked to go to dsdfamilies.org and to familiarise themselves with his condition so that if something occurs, they know about it and are not shocked. I want the parents and adults around to react to A as if

his body development is his own and thus perfectly normal. I asked that all the people involved in his care get training.

Finally, I would like the adult who is there at the awful moment when all the kids point at A and say, 'LOOK! A looks like a GIRL!' and start laughing at him, to tell the children, 'A is different. He does not look like a girl, he looks like A, and that is good. We like A just as he is.'

I told the principal that at this age, the children will take the lead of the adult in charge, and if that adult looks embarrassed or confused the children will know it. If the adult treats it as they would in any case of children who mock another child, then it will be treated as any other case of laughing at someone for having a tear in the knee of his trousers, old shoes, long or short hair, anything.

So, I'm holding my breath, and hoping all will go well. The principal seemed to take my advice on this to heart, seemed to agree with me and will go forward with this plan.

Wish A luck; he will need it.