

## ***Working together to raise happy and confident children with DSD***

Ellie Magritte, [www.dsdfamilies.org](http://www.dsdfamilies.org), [info@dsdfamilies.org](mailto:info@dsdfamilies.org)

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I am the mum of three wonderful children, and live in the UK. My eldest daughter is nearly ten and has PAIS.

I am also the administrator of a new website for parents of children, and teens and young adults with a DSD. The website is called [dsdfamilies.org](http://dsdfamilies.org). It is an on-line resource for parents of affected children and for young people, and for now only in the English language, which combines *accessible medical advice*, ranging from sex assignment to vaginal dilation, written by medical experts, *with practical advice and experiences* contributed by parents and young people who have any kind of DSD.

My paper is titled 'Working together to raise happy and confident children with AIS'. I chose this title because that is, I hope, a key objective for all of us: parents, clinicians, and the adult community and their families.

I suspect however that these words, 'happy, confident' and 'AIS' are rarely combined. But really there is no reason they should not be said together frequently. After all, doing so is how we begin to shape the fulfilling and rich lives we want for our children – by providing an image and reminder of what we are striving for, what we are trying to foster and create.

It is my sense that to be able to raise confident kids, we the parents must find that confidence in us too: the confidence to accept and adapt to the diagnosis, and the confidence in ourselves that we as parents *can make a difference* to the quality of life of our affected child.

So, do *I* have that confidence?

Well, I am not very confident about what has happened in the past, and am not so confident about what must happen in the future. But I am confident about the present, and about what I am doing now to help my child accept her difference.

During this presentation I first revisit the past, the first 7 or 8 years or so of being an AIS mother. I will share my experience of the diagnosis, the isolation that I acutely felt, and some strategies we developed to familiarise our child with her difference. Then, I will try to identify what it is that, presently, makes me feel confident. In a third section, I look at the future, my next 6 years or so of AIS motherhood.

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- *I dedicate this presentation to the memory of my brother-in-law. He always encouraged us to trust our instincts as parents.*
  - *An earlier version of this paper was presented at the meeting of the Spanish support group GRAPSIA, November 2011. You can find a Spanish translation on [www.grapsia.org](http://www.grapsia.org)*
  - *I am grateful to Katrina Karkazis for her comments on this paper.*

## ***The past***

### *The trauma of the diagnosis*

My daughter was born following an emergency caesarean; nobody in the delivery room had noticed anything. It was only the next day that gonads were found in her swollen labia. And even though we established a hereditary link within hours, it would take another 5 days before we would meet clinical experts.

During that time we were subjected to contradiction, incompetence and insensitivities. Twelve days after her birth we agreed with the recommendation to raise our baby as a girl.

The detail of what it is like to have a baby who needs sex assignment warrants an hour long presentation in itself. Ultimately, I don't think it was much different from the experience of any other parent in those circumstances, and you can read one of those experiences on [dsdfamilies.org](http://dsdfamilies.org). The trauma 'softens', but it is still very much there.

A few months ago I was asked by a clinician what happened at my daughter's birth. I think this was the first time anyone had actually asked me. A memory I had relived a hundred times, even written about, but never spoken about out loud.

I tried to explain how I experienced the sex 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.

I sobbed as I was trying to explain this.

Clinicians are now carefully orchestrating 'Information Management', i.e. how and when information is shared about the assignment process and the child's diagnosis with the parents and who shares it.

I'd like to caution against overly controlling this process in favour of raising awareness and sensitivity across all staff who cares for the family.

Let me give you an example: After the Caesarean section whilst still on the maternity ward, I had a typical problem with my bladder function. A young doctor came to check on me, one or twice a day, asking how my *bladder* was. Not once did he ask how my *heart* was doing, how I was doing, how my baby was doing. Even if he simply did not understand DSD, and/or was cautioned against talking to me for fear of misinforming me, or simply did not want to spend 30 min talking with a crying mum, rather **than ignoring the issue that most mattered** he could have said: 'You know, I really don't know much about these conditions, and you really need to be advised by a team of specialists. But I do know that your baby really needs mum now and once you have recovered from childbirth, it will be easier for you to care for your baby.'

I understand that for many parents their sex assignment experience is defined by considerations about surgical interventions. Considerations we are making when we are **at our most disoriented**. We had to make a decision about gonadectomy, and

we decided not to intervene. We felt that the best thing we could do for our daughter was to let her be who she was.

Clinicians have included in their model of best practice the need for psychological support for parents. In reality however, and without further investment in and training of psychologists, these 'models' may only pay lip-service, when really, we need help as soon as DSD is suspected, and we need it urgently.

Where is the reinforcement of these 'visions of best care'? And who is responsible for enforcing them.

A sex assignment process is always going to be traumatic. But perhaps there are a few things that doctors and support resources can do together to make it a bit easier:

- Ensure all *staff on maternity wards* are better briefed about these conditions and get adequate training and support to help parents;
- Remind parents that they have a lovely baby who needs their love, and how *bonding* is the first step to raising a happy, confident child and to building his/her self-esteem;
- Please, Place the affected family *at the heart of the interdisciplinary team* -they are crucial in raising a happy, healthy and confident child. The earlier parents learn and the earlier clinicians acknowledge that they are not passive partners but *active partners* in the care of their child, the sooner they will be able to take control.
- As an affected community we, with your help, need to work harder on *producing supportive, practical materials* that can be handed out early on during the diagnosis;
- And finally, Provide parents following the sex assignment process with *accessibly written documentation* about that diagnostic process. The first step in building parents confidence is ensuring they can understand and articulate the medical aspects of the condition.

### *The isolation*

Not that long ago, as part of an email discussion about the nomenclature debate, a clinician stated 'why should DSD be different from cancer, cleft palate or diabetes?' For everyone within the affected community the answer to this is so obvious.

Let me share with you another personal experience:

Like many other families, my husband and I had decided that the diagnosis was a private matter, and that as far as possible it was to be our daughter's right to decide what others may know.

When my daughter was about two, I met a friend for a coffee. We only just sat down when two other young women, one with her young son, came in the cafe. They knew my friend and joined us at our table. The little boy was very handsome— and I said to

his mum 'Your son has a lovely smile'. The table fell silent. Then this young mum started to explain that her son was born with a cleft palate. The boy had just had his last surgery to correct the cleft palate and in a few months' time everything would be over. Whilst she told me this there were lots of supportive comments from her friends who clearly knew all about this, reinforced how hard it had been, and one put her arm around the young mum in support.

I don't mean to be unsympathetic to parents whose kids are born with a cleft palate, but listening to this young woman was like getting my heart ripped out.

I fought off tears I would not be able to explain, pretending as usual that I was 'fine'. Yet all I wanted to do was to scream out loud that I NEEDED SUPPORT TOO. I needed to be able to talk about my birth experience and my traumas and my worries. I needed someone to reassure me that if my daughter was not that interested in her dolls for a couple of weeks, that was 'normal', and that this did not mean she was going to identify as a boy.

Parents who are isolated and who have very few, if any, people to share ordinary concerns with are prone to self-doubt, and anxiety. This undermines our confidence.

Of course we do want best possible care, just like diabetes, cleft palate and cancer patients – but this best care needs to go hand in hand with recognition of the social context in which we live with these diagnoses, the 364 days a year when we are not in the clinic with our child.

Tackling isolation is not going to be easy, because a lot of it stems from society's ill-informed perceptions of these conditions. Again the affected community and clinicians have an opportunity to work together on this:

- by opening up knowledge about these conditions beyond those affected and the clinicians who support them, to nurture a social environment that is more sensitive to difference.
- by working together on the production of high quality support materials as well as on-line support. This will reduce anxiety in parents, and hopefully also young people when they get diagnosed and/or learn about their condition;
- by nurturing a new confident narrative of having and living with DSD/Intersex; too many of our positive experiences are locked in our inboxes;
- and finally, by referring to peer support when possible and fostering peer support if none is available – encourage your families to connect with other affected families: it is above all these connections that can help parents come to terms with their children's conditions and equip them to work with doctors to do the best for their children.

### *Introducing concepts of difference and adoption*

A final significant component of my first 7/8 years of motherhood is the way that we as parents have been introducing basic concepts of difference to our daughter and what her difference might mean for her.

For example, from very early on I looked for books for children on adoption. My daughter was about 9 months when we found the lovely book by Jamie Lee Curtis 'Tell me again about the night I was born'. The book really spurred us on to find other children books that explored adoption, as well as books about difference like 'Frog is frog' from Max Velthuys and 'Giraffes can't dance' by Giles Andreae.

But I really cannot stress enough how through reading those books I learned to talk with my daughter in an 'age-appropriate' language. It really built up my confidence that I can explain difficult things to her in a way that is not scary. And my daughter has grown up being totally familiar with the idea of adoption, and the idea that we are all different, we all have our own strengths.

This is where we can work together as a European and international affected community: in developing tools, a 'language' even, and children's books to help parents explain these concepts.

My daughter is now a big fan of Jacqueline Wilson, one of the UK's most popular children's authors. This author always writes about children having to learn to live with a particular challenge, and I really like reading these books with her to help her understand that when her young life is sometimes difficult that that is not so strange or unusual, that lots of other kids experience difficult times too, and find a solution to deal with it.

On dsdfamilies.org, you will also find a short account by a Canadian gynaecologist, Lisa Allen, who in writing about disclosure suggests to parents that they practice explaining the condition to their children when they are still a baby. I really get that, and can see how practising from early on can instil confidence in parents. It means you can stop worrying about only having one opportunity to do it and getting it wrong. Also, a child is likely to hear the same message differently every time. Repetition normalizes too; this is just how it is and has always been.

That is a small flavour of my past – perhaps I should call them 'the lonely years'.

### ***The present***

Why I am confident about the present? I think there are 4 parts to this:

1. There is a picture on the home page of dsdfamilies website of '*My Family*'. When one of my kids drew that it really hit home how much I have to be grateful for, and if only I had known this so many years ago... The future can look very bleak for parents who don't receive appropriate support.

That picture made me determined more than anything else to reach out to other parents with a positive message of hope and comfort.

And for the last year or two I have a couple of friends in the city where I live who know about the condition and could not be more supportive.

2. Our child is receiving *excellent evidence-based medical care*. We don't have to ask ourselves if our doctors really have access to most recent research, and we can contact them easily **by email** if we do have a medical question. Being able to trust our doctors to guide us through the difficult decisions we have to make in the long-term interest of our child is a very important source of confidence.

3. Just over a year ago, I joined the AIS-DSD parent email group, facilitated by the American AIS-DSD support group. *Peer support* has at long last given **me self-confidence as well as reassurance**: I learned that I am not alone, not alone at all. And through listening and sharing experiences and strategies with other parents I learnt that there is no script for sharing information about these conditions with my child, and that I cannot get it wrong as long as my child always knows she is loved so very much, and that she can ask me and her dad any questions about herself and about how her body develops, and will develop differently.

4. A final component of my confidence is *experience*. For years I felt like this huge responsibility was put on my shoulders but that there was nowhere for me to help me learn how to deal with it. As Linda, a mum in Canada put it, a few months after her 8 year old daughter was diagnosed with CAIS: 'I look at this as *just* getting a new job, like a big job with a lot of responsibility, but no one is training me, and as I am self-sufficient, I am doing all of the research and training on my own, but I need some support, like a manual or something. I am just feeling a little lost and I can't quit this job, or look for a new one: this is it, my life job, to take care of my girl.'

Just over a year ago, I sat down with my daughter and gave her quite a bit of information about her condition: that she would not grow babies in her tummy, and that she would not be 'bleeding'. We spoke about her vagina (where it was – she has a urogenital sinus), about her clitoris (why it is a bit larger) and about taking medication. Then we started to talk about adoption, and about friends who did not have children...

Once all these things were out in the open, I was no longer a 'keeper of secrets', but I could start mothering my child with AIS in a more pro-active way, empower her to accept herself and learn about herself and her different development.

And my daughter responded to this in a natural way... she feels comfortable asking questions about pretty much anything. A few months after our chat, she told me that a friend in her class had got a book about how the body develops [at puberty], and could she get one too. I honestly told her that for a long time I had been wondering if I should get a book like that, but that I was always worried that she might think she would develop like the girls in the book. And I added that now that she knows that she will develop differently, of course, we can go to the bookshop – and indeed, the next day after school we went to the shop together and got the book.

Giving her access to such a book is one way of helping her understand her difference. And what I try to do is **demystify** everything that has to do with 'typical' development, and as such build up her confidence. So, yes, she is allowed to do 'scientific experiments' like adding water to tampons and pads of various sizes and strengths. When we found ourselves in the supermarket needing to buy pads, I let her choose whilst answering her questions about why there are so many varieties.

And when she came to see me with one of her best friends, asking me –whilst I was preparing dinner- whether I could explain where periods come from, I did not flinch and explained scenarios for girls who do have periods and those who don't. I was very proud of myself afterwards.

Last week, as we were getting ready for school, she saw me taking a contraceptive pill and she asked me 'mum is that to stop you having babies?' I said: yes, sweetheart and I thought great, I can tell her a bit about hormones... but then I got stuck... do I call them female hormones??.. And I got my oestrogen and progesterone confused...so in the end I just said that it was a special hormone that stopped sperm getting to the egg. But I wish I had practiced this with someone, like a role-play to talk about hormones.

I used to be afraid that if I didn't have all the answers to all her questions ready she might worry that something was terribly wrong. Now though, if she asks me an important question that I really would not know how best to answer, I can say to her: 'That is a very good question, but you know, I am not so sure how best to answer that or what the answer is. Would it be OK for you if I think about it and perhaps we can talk about it tonight when I take you to bed or one of the next days'.

As parents we seek to combine a pro-active approach to building up her knowledge with a re-active approach as and when she asks us questions or if the opportunity for giving her further info arises. Our approach as parents would perhaps not suit every family, but we feel it works for our daughter and for us.

### ***The future***

What about the future?

Well, I am quite confident in my ability as a mum to guide my daughter through learning about her condition. But there are some important unknowns... how will puberty affect my relationship with my daughter – at this moment the word teenager instils me with more fear than the word AIS.

And at what pace and how does *she* want to learn about her condition...

I have to remain open-minded and prepared to adapt.

I think my daughter understands that what she has is something private – not wrong, but private. I have never told her she can NOT talk about it with friends, but have always suggested she'd come to me first so we can think of the best way to explain this. From very early on also I have taught her that 'private bits' are exactly that: private.

And although I am firm that I will never tell my child that her condition is or should be a secret, the truth is also that at the same time I am scared of, and lack confidence in other people's reactions.

E.g. my husband and I want to empower our daughter to say to her friends that she is not going to have periods. Articulating this, preparing her for this, dealing with questions about this is not something we are ready for yet, not confident enough yet.

All we know is that not lying about periods, not pretending or being scared of someone finding out, would mean a crucial step in our daughter growing up to become a self-confident young woman.

For a long time, I would have defined my future years as an AIS mum through the prism of 'explaining about the gonads, the xy chromosomes and introducing options for reconstructive and cosmetic surgery'.

But not anymore.

For us the important things to address *and place at the very centre of her care are body image and self-esteem*, two key features in the lives of every adolescent and young adult. Ensuring she comes to understand that having good sex is not the same as having a typical sex anatomy has to be an integral part of that care too.

I am not aware if there is a group of people who are looking at developing, and I mean pro-actively devising, modern, positive, practical, psycho-social strategies for and with young affected people, drawing also from expertise out with DSD and more generally 'ordinary' strategies to support teens.

However encouraging it is to learn of research that uses newest technologies to improve diagnosis and care...from my perspective there is a lot of improvements to be made by communicating more openly and more effectively across research, clinical and affected communities, and by pooling our experience and knowledge.

I hope you will join into that conversation.

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