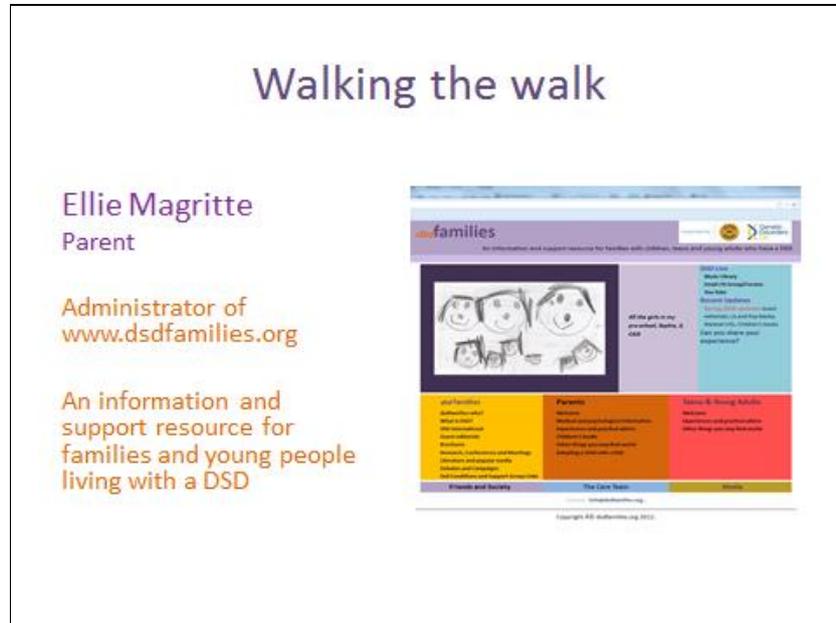


## Walking the walk, by Ellie Magritte

Presented at the I-DSD Conference, 7 June, Glasgow  
(incl PPT presentation)

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I am the parent of three fabulous children. One of the children was diagnosed at birth with having Partial Androgen Insensitivity Syndrome.

I am also Administrator of dsdfamilies.org.

One single parent can not reflect the diversity that lives among the affected community, so I was very pleased that Faisal Ahmed and I, supported by Jillian Bryce, were successful in applying for a grant from the Yorkhill Children's Charity allowing us to invite just under 20 members of the affected community.

Thanks to a grant from the Yorkhill Children's Charity....

...nearly 20 members of the affected community are attending the I-DSD conference....

...including support groups representatives from CAH UK and CAH Ireland, and 'AIS and related' support groups from UK, the US, the Netherlands, Spain, Germany, Italy ...

In addition we are in touch with Support groups in many other countries, incl Australia, South-Africa and Latin America.

I think this is hugely significant, if a little overdue...

As you can see from the slide we have travelled from all over Europe and beyond to join you here in Glasgow.

Our joint experience and expertise in DSD includes....

Living with, or raising children who have:  
CAIS, PAIS, CAH, 5-ARD, Partial Gonadal Dysgenesis, and  
45X0/46XY Mosaicism

- Gender Assignment
- Gender Reassignment
- Living with secrecy and old style 'care'
- Surgery and related issues
- Dilation
- Raising kids with genital difference
- Adoption of kids with a DSD
- Sharing information with kids about their condition
- Running Support groups
- Engaging with media
- Running largest parent email group
- Producing educational resources
- Membership of various scientific boards, steering committee's, etc.

Our joint expertise includes living with AIS and related conditions, gender assignment and reassignment, dilation and moderating the largest DSD parent email group worldwide.

We are well placed to work with you on developing optimal care and support for all those affected and their families.

To make sure you know **who** to approach with **all your burning questions**, could I ask parents and adults to quickly stand up.

This meeting will run parallel to the main programme and is by invitation only

**MEET THE EXPERTS – A JOINT EFFORT**  
Sat 8 June, 9 – 12.30 @ I-DSD conference  
Glasgow

Expertise in dealing with DSD is usually understood as endocrinologists, urologists, psychologists, etc. working together as a Multidisciplinary Team.

But aren't we missing out on the most important discipline? The experts in the everyday life of DSD are those affected by DSD and their families.

So what we need when thinking and talking about optimal care, in all its dimensions, is a joint effort of both kinds of expertise.

This informal meeting brings together our affected community with a more or less equal number of members from the medical community.

Tomorrow morning we will have an informal meeting, parallel to the main programme, to pool our joint expertise and explore issues like care and networking .

Moving on to the main part of my presentation ...walking the walk

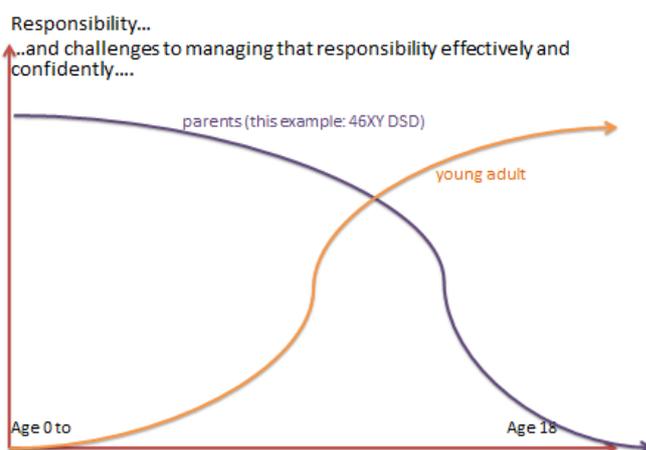
I have tried to map what families experience as some of the key challenges to parenting a child with a DSD...and also –and with the input from dsdfamilies intern Miriam– what the main challenges are to growing up a confident young adult.

These challenges affect our ability to effectively and confidently take on the responsibility of caring for our kids or caring for ourselves.

Now, nothing of what I will say here will be new to you ...you already know that these are the challenges we face, ... you will have experienced it in your clinics, or you will have read about it in Journals, we talk about them and about what we might do...

...we talk the talk easily enough, but we find it much harder to walk the walk, to put our knowledge into practice.

These are the levels of responsibility:



(Slide 6 – 13):

-First big challenge for some of us, Gender assignment, social pressures and medical complexity

-Next big challenge: Lack of accessible and positive information on medical, psychological and practical aspects of DSD, but also on sex and gender;

-Lack of accessible and comprehensive information regarding what surgery can and cannot achieve and of an alternative vision to surgery, i.e. raising kids living with genital difference.

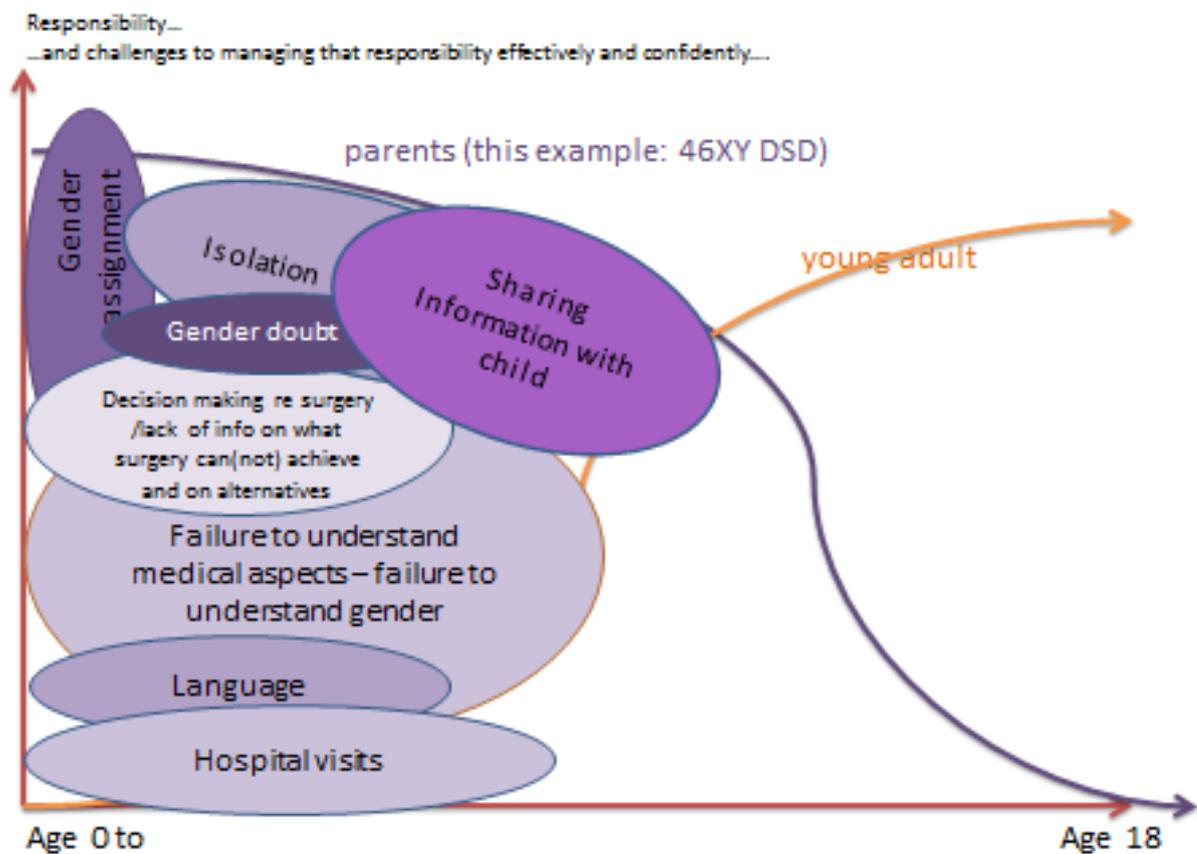
-Stress brought on by comments and language from medics, friends, and sensationalist media

-Hospital visits

-Isolation, fuelling anxiety and stress

-A big challenge for some parents is gender doubt - resulting from a failure to understand gender and having a profound impact on the relationship between parent and child.

-Possibly the main challenge for many parents is how to share information with a child about his or her condition...



(Above: Slide 13)

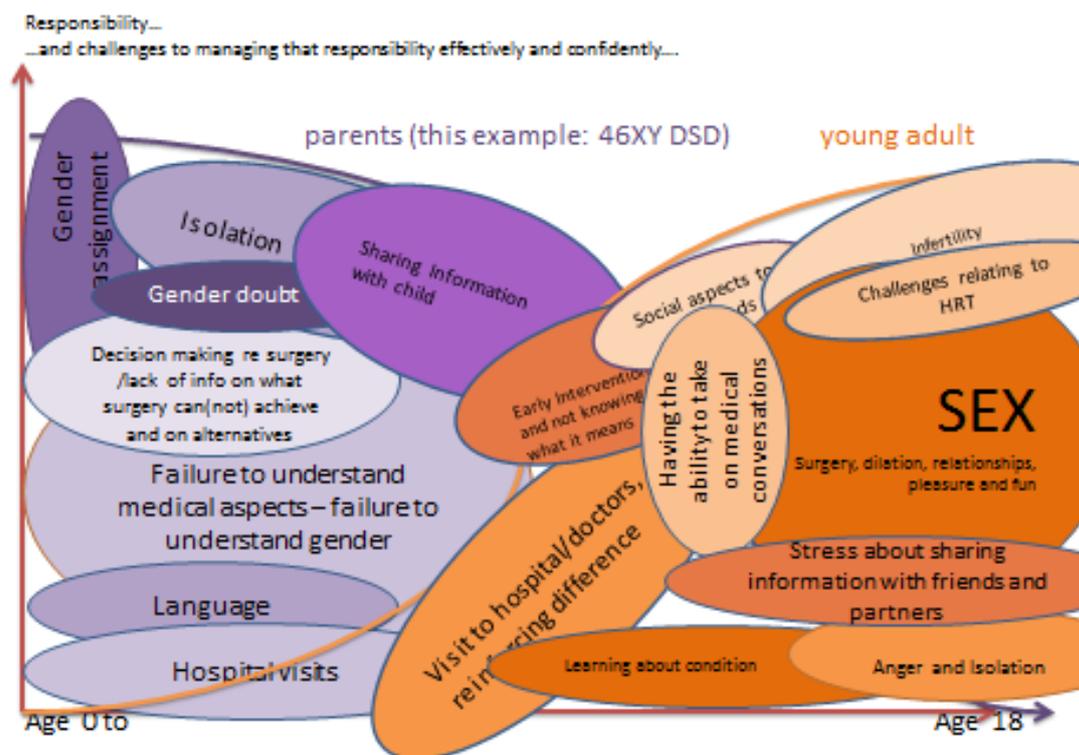
There is nothing there you did not know about, is there?  
But are we doing enough about it?

We talk about it, don't we, but do we really walk the walk as well?

We want our kids to grow up to become happy and confident young adults...resilient, with good self-esteem and a positive body-image...

What are their challenges?

(SLIDE 14 – 23):



- All too often, when parents bring a little child to the MDT who is really coming for help...?? .Let's not confuse care for the parents with care for kids...

-Learning about early surgery and dealing with gonadectomy when you don't know what it means

-Stress about social aspects of not having periods...

-...followed by learning to live with infertility and the worry 'will a partner accept my infertility'...

-Learning about the condition, can be a challenge...but does not need to be; for some understanding the reasons behind hospital visits, surgery etc....can be a relief like in 'is that it?'

-Anger 'why me?'; and just like their parents : Isolation

-Just like parents ...our young adults are challenged by not knowing how best to share this with friends and partners: who , when, what?

-Challenges relating to HRT... how can we work better together in ensuring that HRT mimics what is best, what is natural...?

-It is a big thing for an adolescent to talk about genitals and feelings to a doctor ...are we as parents and doctors equipping them properly....?

And finally: Sex....Surgery and dilation are focused on the functional aspects of sex; where do they go to learn about relationships, and that sex is about pleasure and fun?

(I'd like to make a quick comment here in parenthesis: life does not stop at 18... for many that's when it begins .....

Whilst I am focusing today on working with you to get the foundations right... there are many adults who really need psychological support and dedicated care. I hope we can address those issues too during this conference)

Coming back to my presentation:

Various conditions will identify additional or less challenges..., other people may give more or less weight to some of these challenges than I have done...

But **the majority** of our challenges will be the same. You know this. You write about it.

We talk about it. But do we also walk the walk?

Do we really link up all we know into comprehensive care and support?

So what tools do we, together, have in tackling these challenges? What would walking the walk mean in practice... ?

Here are a few ideas...

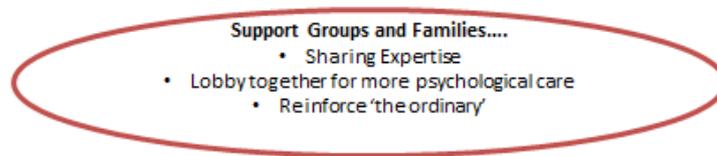
## 1. SUPPORT GROUPS AND FAMILIES

Support Groups have taken on the burden in tackling many of these challenges, and they all too rarely get the recognition for this....

But we can do more:

SLIDE 25-28

### How to tackle these challenges... a few illustrations:



#### **a. Sharing Expertise**

We are the experts in the everyday life of DSD, but we are not always very good at sharing our practical experiences and problem-solving skills **beyond our membership**;

We often slip into complaining about 'what has gone wrong' rather than – also – share what went right.

To develop a new narrative we need more parents and more young people and more adults to share their expertise beyond Facebook and email groups.

#### **b. Lobby together for more psychological care**

Not helped by the varying management plans for various conditions, we fail to look beyond the differences that exist between conditions...when really we have so much in common.

For example, when we all – Hypospadias, CAH, Turner, 46 XY - identify the lack of psychological support for families, young people and adults as a major shortcoming in care, how much more effectively can we lobby for this when we work together....?

If we all petition that psychology should not be 'a last-resort'... 'for those with problems' but a properly integrated part of care that we should seek to deliver in more innovative and creative ways....

If we appeal for more support during transition and more investment in developing adult dsd services...

will we not be more effective and successful?

### **c. Reinforce the 'ordinary'**

Sometimes it seems that all our doctors want to talk about is 'gender, genitalia and genes'.... But WE don't have to..

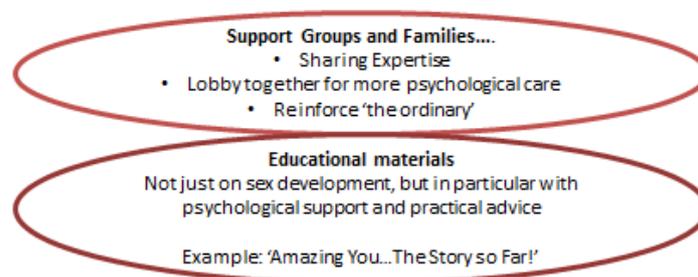
Are we allowing ourselves to get too easily side-tracked by the 'exceptionalism' of DSD .... failing to see that many of our challenges are not so different from 'ordinary life'.

If we can do that, than we can connect with existing resources and support campaigns about body-image and self-esteem, anti-bullying, identity, relationships, ...and adapt them to our needs.

I' d like to put 'ordinary' back into DSD.

## 2. EDUCATIONAL MATERIALS

### How to tackle these challenges... a few illustrations:



Production of educational materials has been systematically highlighted in research as a major priority....

...but all too often we risk that such materials limit themselves to sex development, explaining the 'Normal' versus the 'Wrong', rather than placing the 'Variations' alongside the 'Typical'.

Psychological support is enshrined in the consensus statement as a fundamental aspect of optimal care ...but in reality the provision is inadequate.

You know this.

All of you here representing DSD teams might tick the box on a questionnaire as to whether you provide psychological support...but how much of that really involves psychological expertise in DSD... and how much of that is lip-service, tokenism...?

Educational materials are not so much about sex development. Nor can they ever be an alternative to psychological one-to-one care.

But they can provide a fail-safe level of psychological and practical advice, drawing on our joint expertise of lived and professional experience.

As an example, I'd like to share some pages with you from a visual story I wrote with Dr John Achermann (UCL, London), and with input from other parents and other clinicians...to explain to my daughter how her body developed and what we are to expect.

From 'Amazing you' -- explaining PAIS to my 11 year old daughter

From 'Amazing you' -- explaining PAIS to my 11 year old daughter

The image shows a collage of educational pages from a visual story titled "Amazing you" explaining PAIS to an 11-year-old daughter. The pages are arranged in two rows. The top row contains three pages with text and illustrations. The bottom row contains three pages, including a diagram with a central circle and six surrounding boxes labeled "6 ways".

**Page 1 (Left):** "Amazing you! Be strong as you..."  
 - Title: "Amazing you! Be strong as you..."  
 - Text: "This means an ever-changing mix of genes from both parents..."  
 - Section: "Remember the quizzes you like to do to test suggestions? They are often about personality! Want to do a quiz?"  
 - Text: "Do you like to play sports, read, or draw? Do you like to play video games or watch TV? Do you like to play instruments or dance? Do you like to play board games or puzzles? Do you like to play board games or puzzles? Do you like to play board games or puzzles?"  
 - Section: "No two people are exactly alike!"  
 - Text: "That's why you're so special!"  
 - Section: "1,000,000,000,000"  
 - Text: "That's how many different genes you have!"  
 - Section: "Your body is made of trillions of cells!"  
 - Text: "Each cell has its own set of instructions for how to grow and what to do!"  
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 - Text: "Each cell has its own set of instructions for how to grow and what to do!"

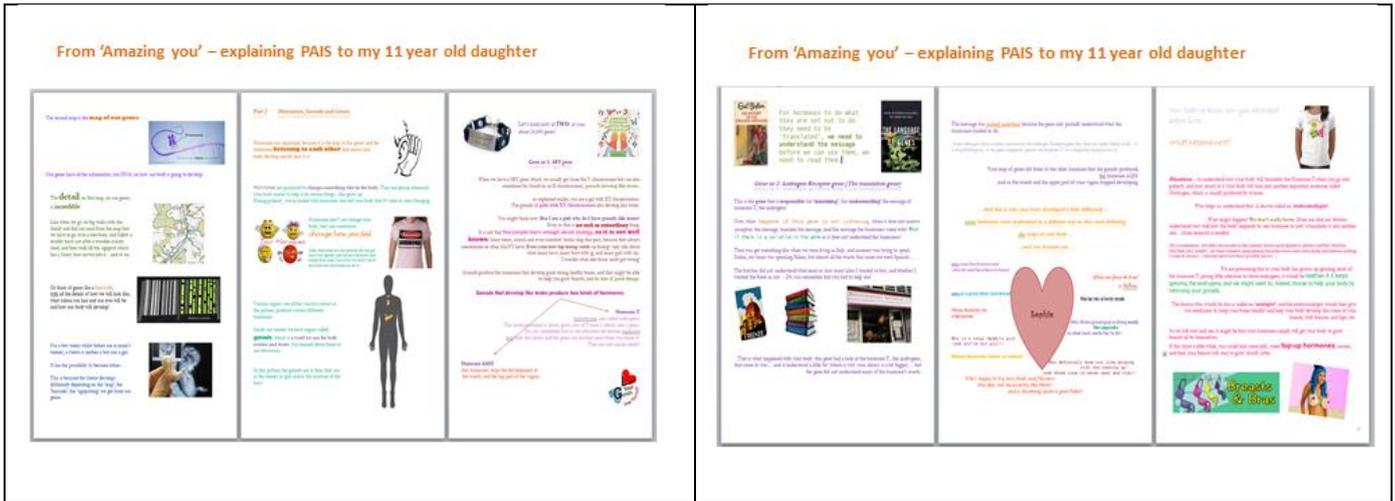
**Page 2 (Middle):** "But for babies we don't know exactly how they'll turn out!"  
 - Title: "But for babies we don't know exactly how they'll turn out!"  
 - Text: "It's a bit like a mystery box..."  
 - Section: "What are we about to find out?"  
 - Text: "We're about to find out how your body will grow and what it will do!"  
 - Section: "Your body is made of trillions of cells!"  
 - Text: "Each cell has its own set of instructions for how to grow and what to do!"

**Page 3 (Right):** "No two people are exactly alike!"  
 - Title: "No two people are exactly alike!"  
 - Text: "That's why you're so special!"  
 - Section: "Your body is made of trillions of cells!"  
 - Text: "Each cell has its own set of instructions for how to grow and what to do!"

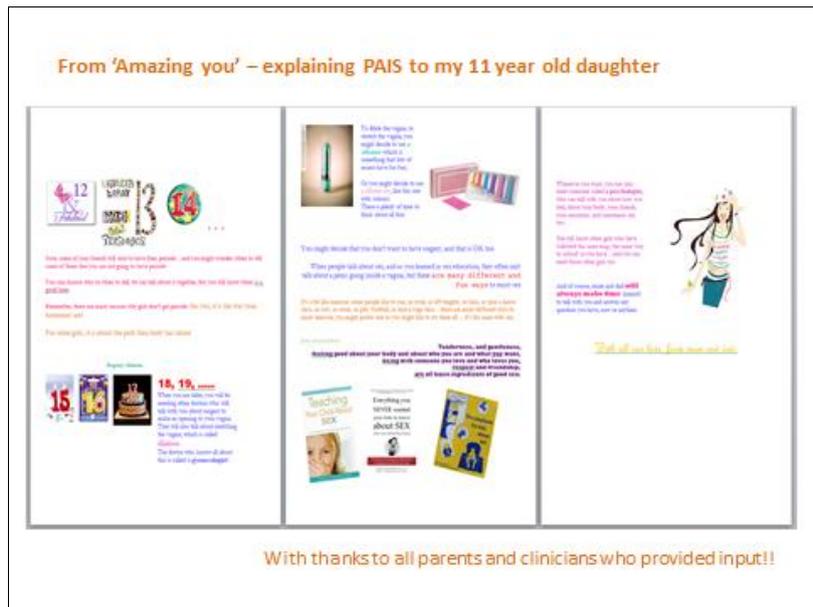
**Page 4 (Left):** "6 ways"  
 - Title: "6 ways"  
 - Text: "There are 6 ways to explain PAIS to your child..."  
 - Section: "1. Use simple language..."  
 - Section: "2. Use visual aids..."  
 - Section: "3. Use stories..."  
 - Section: "4. Use role-play..."  
 - Section: "5. Use games..."  
 - Section: "6. Use art..."

**Page 5 (Middle):** "Before you..."  
 - Title: "Before you..."  
 - Text: "Here are some things to think about..."  
 - Section: "1. Be patient..."  
 - Section: "2. Be honest..."  
 - Section: "3. Be kind..."  
 - Section: "4. Be brave..."

**Page 6 (Right):** "Let's be sure different people have different understandings of sex development..."  
 - Title: "Let's be sure different people have different understandings of sex development..."  
 - Text: "Sex development is a process that happens to everyone..."  
 - Section: "1. It's a process..."  
 - Section: "2. It's different for everyone..."  
 - Section: "3. It's a process..."  
 - Section: "4. It's different for everyone..."



I placed her story in the context of our family and her personality, only using positive, easy-to-understand words presented in a style that engages teens, and using her favourite colours ...even for the vibrator!

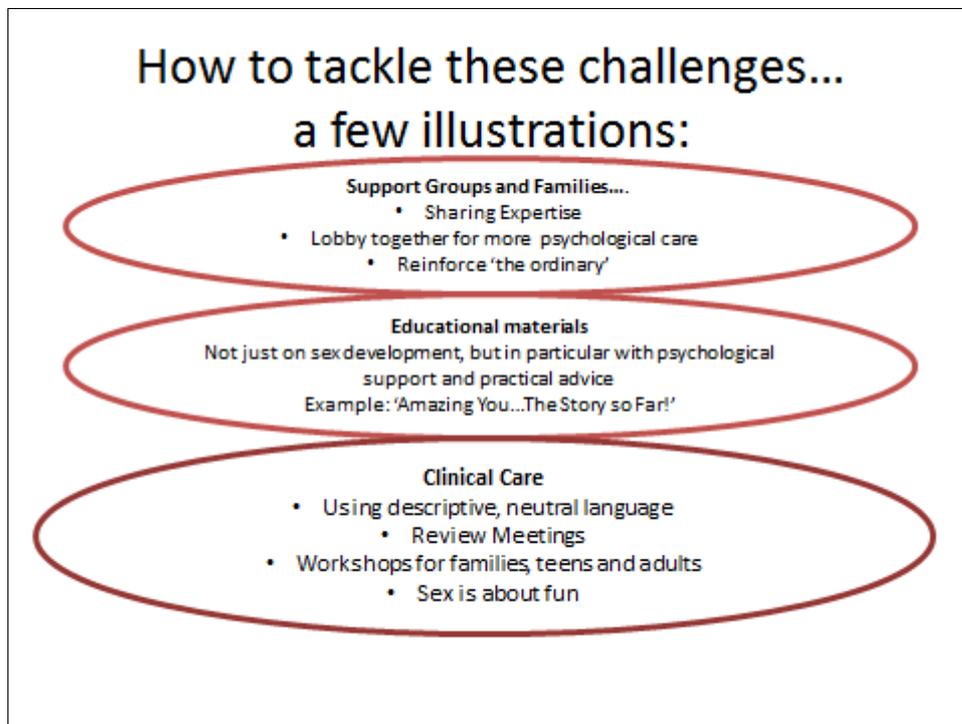


A little while ago, I shared this leaflet with her on a relaxed Sunday morning in mum and dad's big bed: Gonads like testes that do a lot of good things, and xy chromosomes which the school never tells you about... that was not scary to her

I know that for my daughter this is really only a small step in a long journey... but I think we built a strong foundation

We know what we need, now let's put it into practice and walk the walk.

### 3. CLINICAL CARE



Finally, I'd like to introduce four small steps to 'walking the walk' in clinical care:

#### **a. Using Neutral Language**

If you say 'Ellie's glass is half –full' that means something different than when you would say 'Ellie's glass is half-empty'.

That is because the words are value-laden, they often imply something beyond what we mean.

It is the same with the words you use when discussing DSD.

I have made a quick overview on the basis of the abstract booklet of this conference....

## Please use simple, neutral language

Avoid words like:	Use simple words like:
<ul style="list-style-type: none"> <li>▪ Normal/abnormal</li> </ul>	<ul style="list-style-type: none"> <li>▪ Typical/ not so typical/ usual and unusual/ variations and different</li> </ul>
<ul style="list-style-type: none"> <li>▪ Abnormalities/malformations</li> </ul>	<ul style="list-style-type: none"> <li>▪ Difference / anomaly / variance</li> </ul>
<ul style="list-style-type: none"> <li>▪ Ambiguous genitalia</li> </ul>	<ul style="list-style-type: none"> <li>▪ Genital difference</li> </ul>
<ul style="list-style-type: none"> <li>▪ Male foetus, male hormones ...when possibly talking about a girl</li> </ul>	<ul style="list-style-type: none"> <li>▪ XY-foetus, testosterone and androgens</li> </ul>
<ul style="list-style-type: none"> <li>▪ Correction of genitalia</li> </ul>	<ul style="list-style-type: none"> <li>▪ Surgery</li> </ul>
<ul style="list-style-type: none"> <li>▪ Under –masculinisation, under-virilisation...when talking about girls (but also boys! )</li> </ul>	<ul style="list-style-type: none"> <li>▪ Her body responded to the androgens which is why her clitoris is larger than usual; we don't know how her body will respond to androgens/testosterone when she goes into puberty</li> </ul>

Some of you might say, but this is a medical conference, we would not use these words in front of our patients and their families....

But it is **right here** that we develop best practice and that **we set the tone** of how to care, and of what is important in care.

### **b. Review meetings**

Once a diagnosis and early management plan are achieved, there is a danger that the diagnostic team thinks "job done", whereas for the family it is only the start of the journey, the start of a series of challenges.

In addition, doctors may think that because the family has been explained a diagnosis, it's **cemented in everyone's mind forever**...

But traumatic births are not that easily forgotten...and DSD conditions are not learned about after just one explanation.

A review-meeting, some considerable time after the diagnosis, and earlier for affected kids who are **firstborn** than for those who have siblings, can revisit the birth and the assignment process, can revisit the complexities of the condition in a **'every question is a good question'** way, allowing doctors to make sure that parents fully understand the diagnosis, that there is a medium to long term care plan in place and

that parents are fully equipped, emotionally and intellectually, to take on the responsibility of care.

I doubt whether parents are ever in a position to give fully informed consent until such a thorough review has taken place.

### **c. Workshops for parents, teens and young adults**

Last year, I heard Christopher Houk talk about Quality of Life in CAH. As part of his conclusion, he said 'Like other DSD's, outcome appears to be associated with social support, in particular parents and family'. Others have mentioned a similar message.

As always ... we talk about it!

But if we know this....then what are we doing in practice to maximise the benefits of social support... ?

Doctors are **not** responsible for the friends we keep and the family we have, but you can equip us to negotiate some of the challenges which are so specific to DSD, help us develop a language, and help us speak it with confidence and fluency.

Workshops bring together families with experts in an informal atmosphere;

- provide peer support and therefor reduce isolation,
- promote understanding and adaptation, and
- facilitate the exchange of practical strategies for raising a child and
- for sharing information with child, family and friends,

thus making for more relaxed parenting, and better-supported kids.

They can be a place where young people can get to know each other and talk about, learn to talk about their body, relationships, things that matter to them...they can meet their doctors in a more relaxed, informal environment ...and so we equip them to take on the responsibility for their care.

Organising such workshops doesn't cost the earth, they can be hosted by individual teams, or hosted **in partnership with a support group** or a network of hospitals. Feedback forms can help you evaluate them.

All it requires is commitment.

It's not 'talking' about the value of social support ...it's 'walking the walk'

#### d. Sex is for fun

And finally, if 'functionality for sexual intercourse' is such an important consideration at Gender assignment...than why are we not supporting our young people more to learn about self-esteem, relationships and good sex?

If sex is such an important consideration when judging one's Quality of Life... than why are we not investing much more in making sure our young adults have the best possible sex?

Surgery is **never** going to be 'successful' and our Quality of Life studies **never** rosy as long as we only focus on **functionality**, and not on the **really important stuff** like:

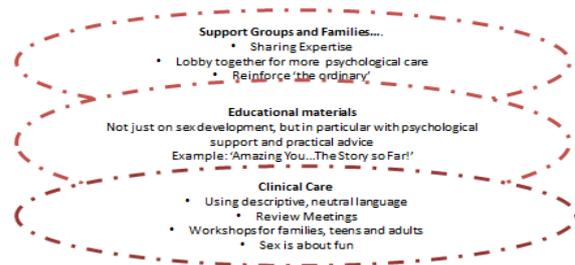
- accepting yourself and the condition you have
- body image and self-esteem,
- social skills and relationships,
- and pleasure and fun –with a partner or by yourself

As well as 'the ordinary', I want us to put 'good sex' back into DSD and to **nurture the knowledge that builds self-esteem ...which provides the basis of the caring relationships that underpin good, fulfilling sex...**

Coming to the end of my presentation... I think these are good illustrations of some small steps we can all take to walk the walk....

There is at least one more thing missing though, and that is **working together in partnership**: frequently, amicably, and constructively...without anyone feeling they are crossing 'enemy lines'.

And that means moving together into a phase of closer collaboration and **much, much** better communication,



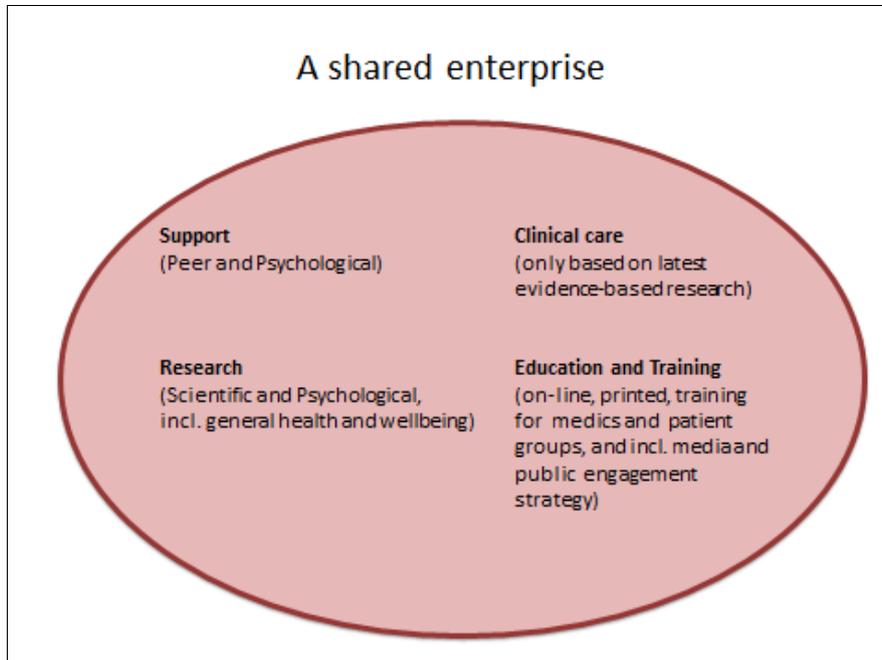
To a point...

...Where everyone works together as part of a shared enterprise to achieve optimal Quality of Life for those affected, and a more positive experience for their families;

...Where lived experience and peer support is valued as much as the expertise of the Multidisciplinary Team.

...Where scientific and psychological research happens, and, supported by all stakeholders, provides....at last...statistically reliable results

...And where there is equal investment in Education and Training as in Research.



Anything else would be an unsatisfactory makeshift, do-it-yourself solution.

But you know all this. You know what we need to do....**You** know it better than **me**.

So let's stop just talking the talk, and let's walk the walk.