

'Listen to us':

dsdfamilies

Consultations with children, young people and families living with different sex development

dsdfamilies 2019



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1. INTRODUCTION

“dsdfamilies” was established in 2011 by two mothers of children with different sex development (dsd). Their experiences had highlighted a lack of information, peer support and psychological support. With these concerns in mind they began - with the enthusiastic support from other families, young people and healthcare providers - to gather, create and distribute relevant information which could assist parents in raising confident, happy and resilient children.

dsdfamilies gained charity status in 2016. The core values have stayed the same, with collaboration, inclusivity and the voices of children and parents central to the charity’s work. Its vision is to develop the informal support network and source of information into a professional support organisation.

In 2017 Children in Need England, Children in Need Wales and Awards for All (Big Lottery) funded dsdfamilies to run a national consultation. This was designed to capture the experiences and views of children with different sex development and those of their parents, caregivers and healthcare providers. The process and outcomes are set out in this report.

The findings from this consultation will play a major role in developing the portfolio of work for dsdfamilies. They will also be widely distributed amongst community organisations, healthcare providers, educational organisations, policy makers, parents and young people. We hope this report will contribute to the understanding of what different sex development is and what it means to children and families. We also hope it will help develop and improve services, practice and societal understanding across the UK.

This consultation and analysis has taken a child-rights/child-centred approach, focusing on the rights afforded to all children under the UN Convention of the Rights of a Child (UNCRC, 1989).

Definitions

There is much debate around the terms used to define people who have developmental or congenital health conditions that affect their hormones and the development of their reproductive organs. After significant debate dsdfamilies has decided to continue to use the term ‘different sex development’ which links to the charity’s name. We acknowledge that this acronym also can mean ‘disorders of sex development’ and that the term ‘disorders’, although commonly used in medicine, has negative connotations elsewhere. We also acknowledge that some adults and young people self-define as Intersex and/or reject medical diagnostic descriptions.

We believe that words matter and can demarcate and stigmatise or they can include people. We will keep reviewing all terminology with stakeholders to foster an understanding of the importance of the words we use to describe things.

Statistics and conditions

Differences of Sex Development is an umbrella term that brings together a range of conditions affecting the development of the genitals and reproductive organs.

In the UK, about 1 in 5000 babies are born with genitals sufficiently different to cast doubt on the instantaneous recognition of birth sex we take for granted. Based on the current birth rate, that means about 140 such babies are born each year in the UK.

In addition, some children will not be diagnosed until they reach puberty. (Ahmed SF, Achermann, JC, Arlt W et al (2016). Society of Endocrinology UK guidance on the initial evaluation of an infant or an adolescent with a suspected disorder of sex development. Clinical Endocrinology 84: 771-788.)

Being born with genital difference means that specialist input is used to understand a baby's biological development. Investigation will include physical external (and sometimes internal) assessment, karyotype tests (looking at chromosomes), blood tests and hormone measurements. All this is used to understand the child's biology and plan whether any health care might be beneficial.

There are many different sex development pathways and a detailed overview is set out on www.dsdfamilies.org. For the purposes of this report and to aid understanding of those new to this field, below are examples of three ways sex can develop differently. The percentages listed are estimates to aid understanding.


Congenital Adrenal Hyperplasia (CAH)

CAH is due to a genetic variation in the adrenal gland and is a group of lifelong medical conditions that leads to people needing daily medication to replace the adrenal hormones not naturally produced (cortisol and aldosterone) and address the overproduction of androgens. The condition occurs in both boys and girls, although the androgen excess can cause genital difference (doctors call this ambiguous genitalia) at birth only in girls.

This group accounts for about 25-30% of children born with genital difference/different sex development.

Girls with a Y chromosome

Girls with XY chromosomes are often not diagnosed until puberty. A girl will have testes or 'streak gonads' (functionless, fibrous tissue that has replaced reproductive tissues) and in many circumstances, will not have a womb or fallopian tubes. Some girls might be able to produce testosterone but their body is unable to respond to it and their body will turn the testosterone into oestrogen. Others have not produced hormones at the usual level for



girls, and may need to take HRT. Some other girls are unexpectedly able to both produce testosterone and respond to it.

This group accounts for about 5-10% of children born with genital difference/different sex development.

Boys with peno-scrotal hypospadias as a result of underlying different sex development

This means that a boy has a small penis with the opening at the base, not at the tip, and a different shaped scrotum. This is sometimes related to underdeveloped testes and reduced production of androgens (testosterone). It includes boys with mixed gonadal dysgenesis ('streak gonads' as mentioned above/ or maybe one streak testis and one typical testis) and boys whose body does not fully respond to testosterone.

This group accounts for about 60-65% of babies born with genital difference/different sex development.

Many conditions can have complete and partial variations, referring to how the testes have developed and the reasons for it or to how the body can respond. Cancer risk of testes varies greatly depending on a person's biological pathway and may need monitoring (usually) post-puberty.

In short, different sex development is diverse in character and complex, requiring individualised care to ensure optimal health, wellbeing and development.

2. REPORT FINDINGS SUMMARY

Over an 18-month period, dsdfamilies consulted with 194 people comprising of children, young people and adults living with different sex development and their families. Differences of sex development is an umbrella name for around 40 heterogeneous congenital conditions that can affect genital and/or reproductive development.

The consultation included Family Day events, online and paper questionnaires and two national focus groups in London. In total 72 children and young people were engaged in this process.

Through the consultation process, children and parents said they want a voice in care and service planning and that they need healthcare services to work in partnership with them. They want the opportunity to meet others and share experiences; they need wide-ranging reliable information and specifically identified skilled psychological care as essential. They need non-specialist health services to have a better understanding of differences of sex development, and they also need this within education, with policy makers, and in the public realm.

Children and young people said they need:

- Clear, child or youth friendly information so they can understand their condition better.
- Emotional and psychological support as part of health care with psychologists working with every family.
- To meet other young people for peer support, in different ways to suit different people.
- Their parents to be supported.
- Public awareness so that their experience is known and understanding.
- School PHSE/biology teachers to understand that differences of sex development exist.

Parents and caregivers said they need:

- Supportive healthcare staff (specialist and non-specialist), because their absence is harmful
- Standard quality care around the country including regular medical and psychological appointments to help their child understand how they developed
- Access to a psychologist for children and parents
- Peer support events to meet other families and support each other
- Information about their condition-specific management and research and what to expect throughout life
- Clear and honest communication during assessment and diagnosis then time for

- questions- not rushed decisions
- Support to talk to their child about their health condition, positive sex education and building resilience
 - Clear transition support for children leaving paediatrics
 - School to be better informed to provide sensitive PSHE/Biology education
 - To know their child is safe in a school that can handle a medical emergency
 - Public understanding of differences of sex development without 'othering'.

Adults with different sex development said they would have liked as children:

- Clear and detailed information at different ages
- Meaningful conversations that start in childhood
- To meet others - 10 adults had not met someone with the same or similar health condition

Health care professionals said the families they support need:

- A range of support options, including multi-disciplinary & peer support
- Information resources to give to families
- Knowledge and understanding amongst non-specialist healthcare providers
- Readily available psychological support for families.
- Public knowledge and reduced stigma.

The consultation outcomes produced 20 recommendations that will inform the dsdfamilies 2019-2022 work programme and fundraising strategy.

The report and its observations also serve to inform key stakeholders in healthcare, government and fundraising bodies of the clearly articulated and shared needs of children, young people and adults living with different sex development and their families.

3. THE CONSULTATION PROCESS

dsd families engaged four freelance consultants with expertise in social work, psychology, children's rights, youth participation and advocacy to run the consultation. This group, with the practical support of dsd families trustees, developed an initial plan for consulting with children, families and professionals. In response to feedback from healthcare providers, elements of this plan were altered and the final consultation activities consisted of:

- Outreach to engage healthcare providers at events and conferences
- Online and paper questionnaires
- 'Family Day' consultation events
- Youth residential weekend

Outreach to professionals

The support of healthcare providers who have regular contact with children and families was essential. Having an excellent reputation for providing high quality information, dsd families was able to ask healthcare providers to work with the charity in reaching out to children and parents affected by differences of sex development.

Representatives of the charity attended meetings and conferences, presenting the consultation plan and asking for support with this process. Staff and trustees made presentations to the British Society of Paediatric Endocrinology and Diabetes (BSPED) DSD special interest group and attended the BSPED Annual Conference. They also attended specific targeted

meetings and visited key clinical teams. The response to these presentations was varied. Many understood the need for this work and were eager to engage. Others questioned the value of the consultation process and did not agree that the children and families had an unmet need. Thus, the help offered to reach out to children and families by healthcare providers varied greatly.

Questionnaires

Online and paper questionnaires were developed for four different groups:

- Children and young people with differences of sex development
- The parents and caregivers of these children
- Adults born with differences of sex development
- Healthcare providers



All the questionnaires followed a similar format with the focus on information and support needs. Once live, these questionnaires were promoted through established health networks (BSPED); healthcare providers who had engaged with dsdfamilies in the past and utilising the small database of families that dsdfamilies had built up. "Living with CAH" (the charity supporting families whose child has CAH) also promoted the questionnaires on their forum, as did the Facebook groups supporting people with Hypospadias.

Family Days

This was a model suggested by healthcare providers who had used it to engage families in the past. Therefore, this model was replicated with a focus on facilitated consultation.

Each day consisted of:

- Facilitated group discussion separating the parents and children
- At least one fun activities, from holding the meeting in a local attraction with free access afterwards, circus skills run by clowns, a magician and access to a swimming pool.
- A communal meal



In total, 52 parents and caregivers and 44 infants, children and young people attended the Family Days. These were held in three regions: South West England, North West England and South Wales, although families that wanted to attend from outside these regions were supported to do so.

All events were promoted nationally through the same networks as the questionnaires. dsdfamilies collaborated with the local healthcare team to develop and promote each event, which included distributing leaflets and clinical staff attending.

Each family day focused on creating a comfortable and fun

environment for the children and their families so that they could feel relaxed and interact. By meeting informally, families gained the means to link up and build peer networks. Many phone numbers were shared and we have had reports since of families keeping in touch.

Youth weekend

The final planned activity was a youth weekend where young people would come together from around the country to look at the findings from the consultations and make their recommendations. Although 9 young people initially signed up to attend, all but 2 pulled out so the event had to be cancelled. We discuss this later in the report.

Government Equalities Office Focus Group

In agreement with the funders, dsdfamilies undertook some outreach work to support young people and parents to take part in a focus group in London hosted by the Government Equalities Office (GEO). This was held on 18 February 2019 and part of the 'Call for Evidence' on what the GEO has defined as Variations of Sex Characteristics (VSC). The discussion of the focus group followed similar topic areas to the Family Days and concluded with the young people writing a 'charter' (included in the following section).



4. FINDINGS: YOUNG PEOPLE GROWING UP WITH DIFFERENCES OF SEX DEVELOPMENT

Growing up with any health condition can present a child with many challenges. This can include managing medication, time out of school for appointments and sometimes needing to explain their condition and the ways it impacts on their life. There is a small group of health conditions that still encounter social stigma. This means that children and young people may feel they need to manage these with some secrecy. This can create additional problems including feeling isolated and different.

The process of engaging children and young people in this consultation has provided as much of an insight into their experiences as the information they themselves have given. This will be reflected upon after presenting the findings.

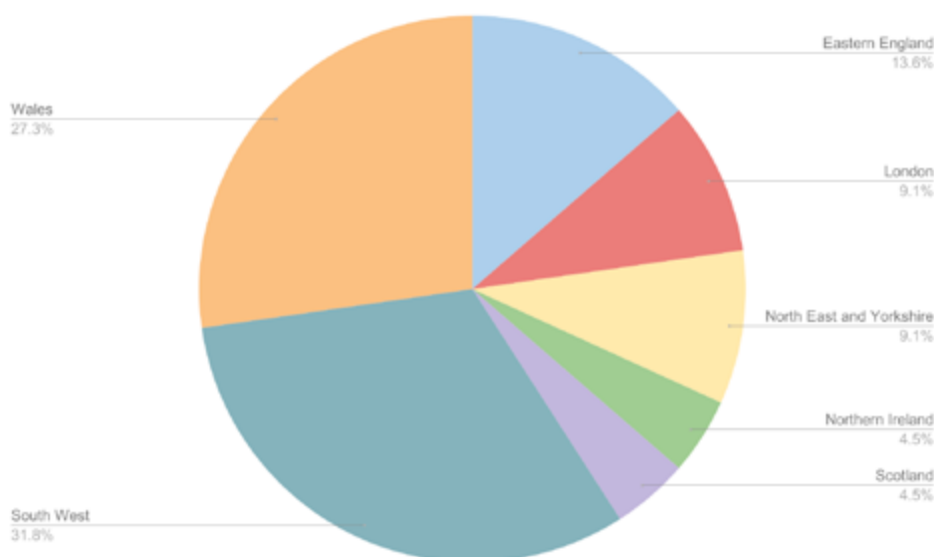


Consultation Activity: Online and paper questionnaires

A short, youth-friendly questionnaire was drafted and sent to the established community and health professional networks listed in the introduction.

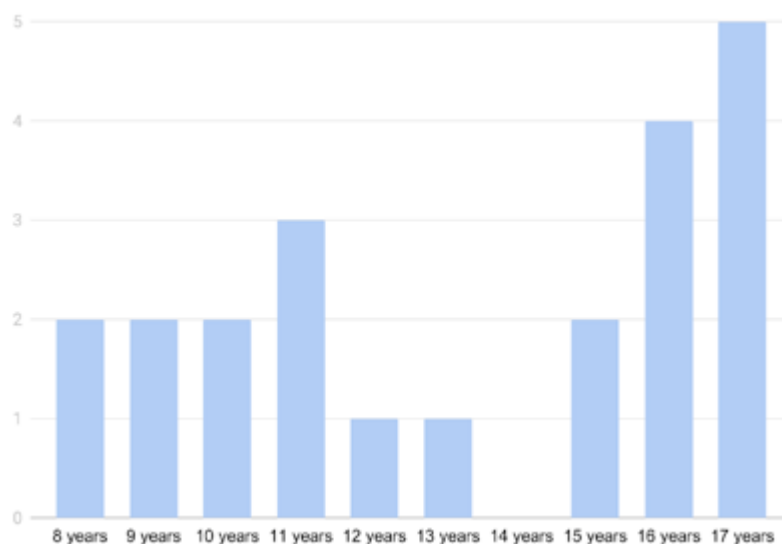
We received 22 responses, (n=11) online and (n=11) in paper. Table 1 provides the geographical breakdown of these, and table 2 the age breakdown.

Table 1. Geographical breakdown of respondents



When I was about 13 I went to A&E because I hit my head. The doctor asked if I was taking any medication. When I told him what I was taking and why, he got really excited and said 'I've never met anyone with that before, could I have a look?' He basically wanted to look at my vagina, even though I was there with possible concussion. My dad made a formal complaint.

Table 2. Age breakdown of respondents



There was a large age range of those responding to the questionnaire. Younger children focused mainly on the information and support they would like, whereas the older children were more reflective of their experiences.

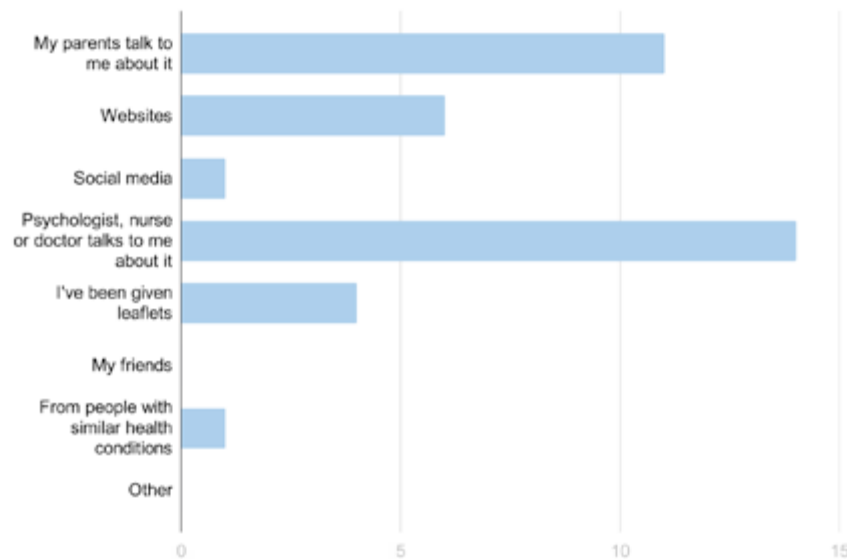
Of the 22 young people that completed the survey, (n=11) said they knew the name of their health condition and (n=1) said they did not.

They were then asked about being told about their health condition. (n=11) of the respondents answered the question. (n=5) said they were told by a doctor and (n=6) by a parent(s).

The young people were then asked from where they gained information about their health,

and were provided with a list of options from which they could choose multiple responses. Table 3 shows the responses of the (n=16) who answered this question.

Table 3. Where I get information about my health



They were then asked if they would like more information and 55% said 'yes'. This group were asked what sort of information they would like and this fell into two main areas.

More medical information:

"Details. It's very complicated so only a doctor really understands it"

"What condition I actually have. I don't have a name after multiple different diagnoses"

The second was psychological and social issues:

"How to accept myself"

"About talking to my friends about this"

They were then asked if there was anything that would make their condition easier to understand. 11 responded to this with (n=5) saying 'no' and (n=6) talked about either

'society' or reiterated 'information'.

"More publicity about it, coverage of what it actually is and the clear difference to the other things/health conditions (such as transgender people)"

"Having dsd conditions discussed in schools"

"There's no information!"

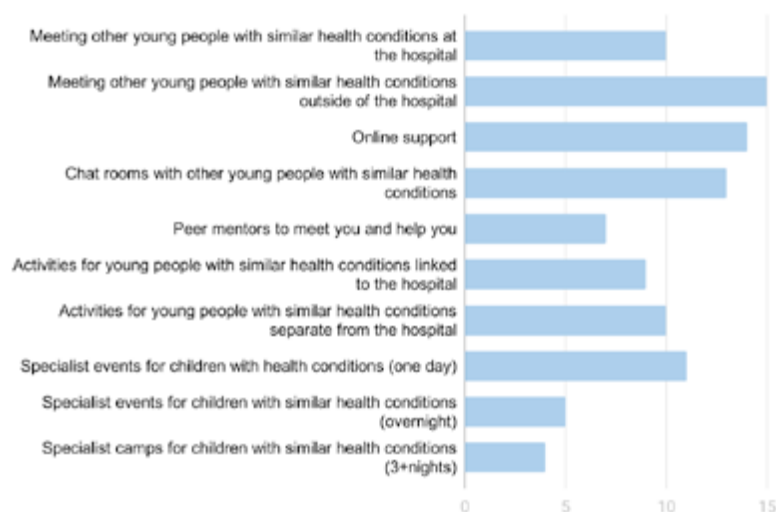
"Can't trust online information"

"Diagrams"

When asked if they had ever met another person with a similar or same health condition, of the 22 responses, (n=10) said 'no' and (n=2) said 'yes'. This question did not specify whether the person they had met was a sibling, as it is not unusual for families to have multiple children with the same health condition.

They were then asked would they like to meet other young people that share their experience and of the 22 responses, (n=21) said 'yes' and (n=1) said 'no'. They were then given the opportunity to choose multiple ways they could meet. Their responses are shown in Table 4.

Table 4. What support would you like to have available to you



Finally, the young people were asked if they had anything else they wanted to say. Only two young people completed this section (other than those that said 'no'):

"I'm not sure if I want to go to something outside the hospital, it would depend on who knows about my condition"

"I love you all :)"

The questionnaires present some very clear messages from the young people that completed them. The strongest of these was that 95% want to meet other young people with similar health conditions.

Consultation Activity: Family Days & Focus Group

"Talking about it makes you feel better"

At the three family days, a total of 44 infants, children and young people attended. The Focus Group in London consisted of 7 young people aged between 12-16 years of age (1 had attended a Family Day). There was also an older young person (19 years of age) who supported the group in a peer-mentoring capacity but also contributed to the conversations.

There were various discussions had at these events and the findings of these cover the following areas:

- In the clinic
- At home
- Talking with peers
- Schools and the community
- Support in the future: meeting up
- Support in the future: Information
- Support for their parents

In the clinic

Most of those who attended over the age of 8 were aware of their health condition and could name it. They spoke about their experiences in the clinic, who they saw, who spoke to them and what they felt about this experience.

Some children reported their parent(s) were almost always with them during consultations and that sometimes they had to wait in the waiting room while the doctor spoke to their parent(s) alone. Some said they were informed afterwards about what was discussed, whereas others said they were not.

“The doctor tells my mum the details and the complicated parts and then they tell me”

Discussion showed that the children attending the consultation were well informed about their respective health conditions (knowing medical names and some biological information ‘I have gonads inside my body’). But their knowledge of what might happen due to their health was more limited, such as possible surgery and changes in their body.

The level of knowledge and understanding will reflect the self-selected cohort reached through this process. These children are from families who wanted to engage, wanted to share experiences and wanted their children to meet others. The levels of knowledge in this group may not reflect that of the wider population of children with differences of sex development.

When talking about the information they were given, most young people said they wanted to be better informed, have things explained to them in a clearer and more complete way.

“I sometimes understood what [my doctor says]. I don’t really understand most of the doctor stuff. But I’m trying to learn it”

Others spoke about how at medical appointments, if their doctor did not engage them and explain things in a way they understood, they would switch-off.

“At appointments I just keep quiet”

Not all the young people who attended the family days have access to a psychologist. Those that did spoke about the impact of this:

“[My psychologist] is someone I trust. She’s the only one I talk to at the hospital”.

“I like going to the hospital when I am talking about things that are stressful and hard for me”.

At one Family Day, one group set out their definition of a ‘good’ doctor:

A good doctor:

- Talks to you and not your parent
- Feels like they are on your side and doing things for you
- Acts like they are interested in you

Another young person described what they particularly wanted from their clinical team:

"[That] they are calm, keep you concentrated and let you know you can be yourself. They are kind, helpful and funny... and they make you laugh!"

When asked where they got the questions about their health answered, those that did share, spoke about their family rather than through their healthcare providers. *'My mum [answers my questions]'*. Some had older siblings with the same condition, *'I talk to my sister as she has the same condition as me'*.

The focus group undertook an activity in two groups to look at who they had contact with through their hospital. Both groups listed 'psychologist', although in one group no one there had ever seen one, but they had 'heard about them'. The two people present that have psychological support described this to the others:

"It's like there's someone there just for you. You can talk about whatever you like, things you don't want to talk to your parents or doctor about. You can see them when you like, when you need them"

All agreed that this was something they wanted and would benefit them.

The family day discussions offer some feedback relating to the clinical experiences of this group of young people. A clear message was a request for health appointments to be child-centred and engaging, allowing them be involved in discussions and be informed.

They described some of their experiences of not being involved in such conversations, highlighting the need to support parents and healthcare providers in developing the skills and language to do this (something which is also reflected in the parents' consultation). The children also said they want those providing their healthcare to be kind, to listen and to be fun.

The focus group reiterated this in a clear list of what they wanted:

- Health appointments need to be child-centred, about us and engaging us
- Give us information, even when we are young, make it clear and understandable, but still inform us
- Hold 'youth' clinics, even if this means just inviting young people all at the same time
- We need appointments after school or in holidays - we don't want to have bad attendance and be asked lots of questions.
- Smile – be friendly
- Listen to us

At home

The young people at all events spoke about their families and the level of knowledge and understanding they have. Picture activities were used with some groups to help them think about who their family is and what is spoken about and shared there.

The knowledge and understanding within the family about the child's health, and therefore the conversations had in the home, differed between children. For some, the whole family was aware of their health condition and this was due to either there being multiple siblings sharing the condition, or that they had chosen to tell their sibling.

"I'm the same as [name], so she tells me. And mum talks to her too"

There were other young people that spoke about feeling 'out of control' of the information about their health. The picture exercise highlighted the different families children were living in and some spoke of parents separating and having new partners involved in their lives.

"I don't like his girlfriend knowing about me, she tells people - not people we know"



One young person spoke of how her mum told her aunt and now she refused to see her aunt as she asks inappropriate and insensitive questions, "She asks me questions which are about my vagina!"

Some of the young people shared experiences of trying to talk to their siblings about their health condition, but feeling ill prepared. One young person said they had tried,

"Even though I showed them pictures, it was like they just didn't want to understand... they didn't want to listen"

Some shared concerns over telling siblings and the support their sibling might need.

"I don't know what support or information I can get to help them in the future".

Others were unclear who knew what in their family,

“Mum knows.... I’m not sure who knows and who doesn’t know”

Various experiences in the home were shared, but it was clear that open discussions and being able to ask questions were very important. With ‘who knows’, there was a fine line between information being shared to underline that there is nothing wrong with having different sex development, coupled with young people who felt out of control of information about their health and who it was shared with. This issue was also highlighted in the parent groups and is set out in the next section.

Talking with peers

There were various experiences of talking to or not talking to peers about their health. Some were in relationships and had experiences of telling friends:

“ I told a friend. He was being bullied, being called ‘gay’ and I was being picked on as well.”

“When I was younger, I never spoke to anyone, but as I’ve got older I’ve shared it with lots of my friends”

“I told my friend at [primary] school and she shared it with lots of people, so I decided to go to a secondary school where no one from my primary went”

Whereas others had never spoken about their condition outside of the conversations they had with their health team and parent(s). A common response was:

“I haven’t told anyone. I don’t want to. It’s private”

A few of the young people that attended events were in relationships. They shared the experience of telling their partner about their health condition.

“I sat my boyfriend down and told him the name and that I was a bit different down there. I then threw him the laptop and said ‘Google it’ and then ask me questions later”

All these young people had had positive experiences with partners, and spoke about fearing rejection, but finding that the people loved them for who they were, not ‘how my genitals look’.

We know that adolescence is a time when young people further develop their identity and part of this is sharing their intimate feelings and experiences with their peers in preference to their family. Where health conditions are socially stigmatised, this can present a complex situation for the young person who may want to share this information, but fears how others might respond.

Some young people may have been told as a child to not 'show' or 'share' areas of their health. This can then mean they do not feel equipped to share information they may want to later on. There is also a need to build resilience and be prepared for positive and negative experiences.

Schools and the community

As set out in the introduction, there are many different types of differences of sex development and some of these need close medical management whereas others do not.

When talking about what information schools know and their experiences there, some of the young people with CAH answered that *'their mum'* had to inform school, because of the possibility that they might have a salt wasting crisis and would need emergency medication.

Some of those that do not need regular medicines or emergency treatment felt it was *'private business'*. Others were unclear about whether schools knew or not.

There was discussion about young people's experience of sex and relationship education. The consensus was that this took a very *'black and white'* approach.

"[The teacher] said 'every girl has periods', but I know I won't...they told us to draw a 'normal boy and a normal girl'... I felt really angry and got upset.

A number of young people reported being in classes where they were told to draw a 'normal girl and boy'. Another young person shared how their school was aware of their condition and then they were treated differently.

"The head teacher came and took me out of a sex ed class. She said, 'this will upset you', I said it wouldn't, but she took me out anyway. Afterwards, everyone wanted to know why she took me".

Because differences of sex development are rare this, coupled with the lack of public information, means that very little may be known or understood outside of the people living with these conditions and specialist health professionals. Addressing this would make

a significant difference to individuals' experiences as well as challenging perceptions and alleviating fears of, and experienced, stigma.

The focus group discussed at length this feeling of 'difference' and how they felt like a 'curiosity', which was part of the reason they did not want schools to know.

"My friend got diabetes and the school now treat them really differently."

They also spoke about when schools do not know and they have time off for medical appointments which is marked as an 'absence' and being 'lectured' about their attendance.

The focus group were clear that they:

- Did not want to be removed from sex education classes
- Want to be treated like everyone else
- Want differences of sex development as part of the curriculum, but not as a 'special' topic, just acknowledged.
- Want teachers to not generalise - everyone is not the same, not everyone will have periods, be able to have their own children and all bodies are different.
- As stated above, they would like medical appointments outside of school time.

Support in the future: meeting up

"It's good meeting up like this, everyone understand, you don't have to explain anything"



When asked about whether they had met other young people living with similar health conditions until this Family Day, for the majority the answer was 'no'. At the focus group, half the young people had met others and half had not.

"I've never met anyone else. It can feel lonely. I am very glad I came today and have made new friends"

Other than having siblings with a similar condition, only one participant had ever met another young person in the past,

'We got on straight away... I don't know why... We didn't talk about [our health condition].... but it just felt good'

All the young people were keen to have future meet ups. There were multiple suggestions of what these could be, listed below:

- More Family Days and events families can attend together
- A regular group with activities
- One group suggested a big national event, which included small group time for condition specific information as there are so many different conditions that present different medical issues.

"I think a big meeting for similar conditions – with the chance to learn about my condition".

- Another group suggested a large meeting but with age specific groups: 7-11; 12- 15; 16-18

'It would be good to have groups for younger and older kids, so we can talk about the things going on in our lives'

- One-to-one support
- Mentors who were slightly older young people:

'I would like to be mentored by someone a little older who had been through similar stuff'

- Being 'buddied' up with someone the same age.

"I could talk to them about it. We could learn stuff together"

Hearing from adults with the same condition:

"It would be interesting to hear from grown ups that have it. What it was like for them."

- Camps similar to those provided for children with other health conditions, whether these are just for a day or weekend. Some of the young people said they would like their parents to be nearby, *"I'd like them there on the trip, near by. Like here, not in the activity"* where as others said their parents should *"wave them off at the bus stop"*.

There was a strong message that this group of children and young people definitely want the opportunity to meet others. Their suggestions reflect psychosocial support available to

children and young people with other health conditions, involving organised activities that include the opportunity to learn and talk to each other.

Support in the future: Information

All the young people spoke about needing better information. This was information given out at the clinic and information they can access online:

“Clear, youth friendly information that I can understand”

They appreciated that some of the conditions are ‘unusual’, but that they still wanted to understand as much as possible about them.

“I would like to understand it. But I don’t know how to. I’m trying to and I want to”



They said they would like to be given leaflets, information sheets and access to online information that they can look at with their doctors, parents or on their own. Like those who completed the questionnaires, these groups of young people are well informed to a point, but wanted to know and understand more. This knowledge could increase their understanding and support them to feel able to explain their condition to others when they choose. It may reduce fear of the unknown and how this impacts on their self-esteem and emotional well-being.

Support for their parents

This group of children and young people were aware of the impact their health condition has on their parents. They spoke about how their parents emotional response about their health condition sometimes impacted on them.

“They feel guilty. They feel like it’s their fault”

“My Mum can get so emotional. I can’t tell her how I’m feeling about it all, she’d just get upset. But I’m lucky because I can talk to my Dad”

Some spoke about feeling 'over protected' and treated differently from their siblings. At the Family Days this was brought up as an area of support that needed to be developed.

"My parents need something too - they need to talk"

Although this was not explored in any great detail, it does highlight how many of the young people know that their health needs have an emotional impact on their family. This is not unique to differences of sex development. If a parent becomes upset at hospital appointments, a child can interpret this as meaning there is something serious to worry about. This scenario underlines the need to help parents come to terms with their child's diagnosis and then focus on their child's needs.

Support should be family-focused, but with the child's needs at the centre. Children can develop behaviours via modelling parents. Supporting parents' understanding and acceptance at an early stage should promote better understanding, acceptance, and better mental health in the long term.

Our charter

On the 18th February 2019, 7 young people who have differences of sex development came together in London for a focus group with the Government Equality Office. At the end, they set out the follow.

From SOCIETY, we want you to:

- Treat us equally
- Accept us

And we need the public to be educated on rare conditions

From our HEALTH CARE, we want:

- Things about our conditions to be explained to us in a way we understand
- Our appointments to be about us and be young person friendly
- Access to a psychologist, we need someone to talk to

From SCHOOLS, we need you to:

- Know that things aren't always 'black and white' in sex education
- Acknowledge differences when you are teaching, different bodies and different experiences

Conclusions

Organisations supporting children with health conditions have well established support mechanisms in place, including groups, camps, online information, forums and apps. For example the Children's HIV Association run an annual support camp, a family conference and a website for young people. Diabetes UK run 'Family Weekenders', and has web information for young people. Over The Wall is a UK charity that runs free camps for children with long term health condition and is happy to manage confidentiality and information sharing to ensure all children can access this. The benefits of some of these interventions have been shown to create psychological change and build condition-based communities for children (CHIVA Freedom To Be 2015: Final Evaluation Report. Royal Holloway University. Lut & Evangelini 2016).

Children growing up with different sex development are significantly underserved in this area and the young people raised this throughout the consultations. The needs identified were echoed in the consultations with the adults with different sex development, parents and professionals.

This is a group of children that are unheard and, due to the social stigma they potentially face, silenced. This can create high levels of anxiety around attending events and speaking outside of the family or with healthcare providers. There were last minute cancellations at each Family Day due to a young person refusing to attend. At one event, a young person became so upset by the thought of speaking in a group that they sat outside the room and would not come in.

Support services are critical but many young people will need substantial support to engage and access them. To make this successful – as with so many other health conditions – a firm partnership needs to be built with healthcare providers. It is crucial that families know that accessing support is an integral part of their child's care pathway. Once available, support services needs to be normalised, promoted and encouraged by trusted healthcare providers.

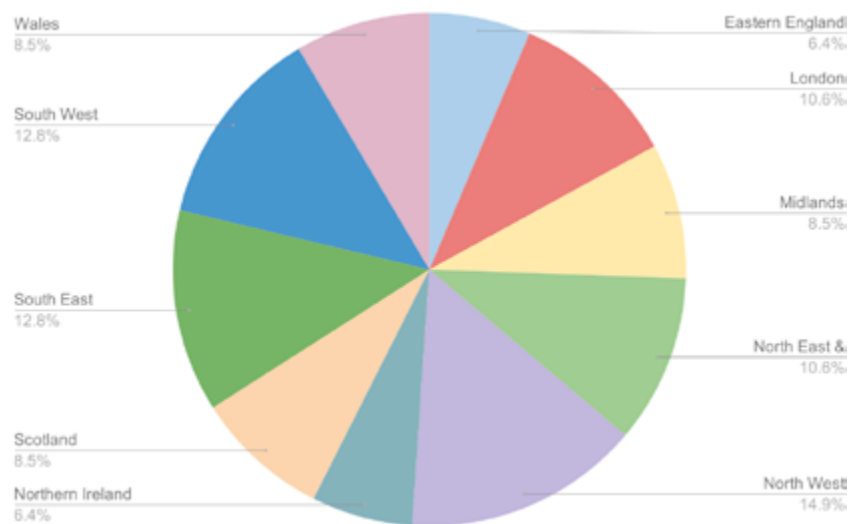
5. FINDINGS: THE EXPERIENCES AND NEEDS OF PARENTS AND CAREGIVERS

This section sets out the responses and discussions of parents and caregivers from the online survey and the family days. This group will be referred to as 'parents', which includes legal guardians and caregivers.

Consultation activity: Online and paper questionnaires

The online survey for parents by far attracted the most respondents, with 47 people taking part in total. Table 5 sets out their geographic spread.

Table 5. Geographical spread of responses from parents



As the above demonstrates, there was representation from across the four nations.

Of the 47 responses, 8 had more than one child with a difference in sex development. Therefore in total, these parents represented the experiences of 56 children and young people.

Parents support needs

All 47 responded to the question of whether at the point of their child's diagnosis they received enough. (n=21) said 'no', (n=19) 'yes' (n=7) and 'not sure'.

They were then asked to share what had helped them at this time. (n=33) answered this question and their responses fell into two categories– support and information.

Supportive healthcare staff

A positive experience from healthcare providers was an important element that helped some parents.

*“***Access to paediatric psychology service***”*

“Amazing team of doctors, geneticists & psychologist”

“A couple of good nurses”

Support from other parents, friends and family

Some parent reported that the support they had received from their family, friends and other parents with children with differences of sex development had helped.

“I accessed AISSG myself and got a lot of support...it made me feel not alone”.



“[What helped was] to have immediate access to support groups. I had to use Google, which we were told not to as there were ‘horror stories’. The Dr actually said not to contact anyone just yet and to wait a while!”

A few parents spoke of how this was the support they would have liked to have had access to:

“It would have been useful to talk with other parents of a child (or an adult) who had a similar level of condition.”

Information

Clear information and ‘things explained in simple terms’ was mentioned by many as being helpful.

“We had a prospective diagnosis quite quickly, and at 6 days old it was confirmed. Knowing what it was and what the options for treatment were quickly made things a lot easier”.

A few parents responded to the question of 'what helped' by saying 'nothing'

'Nothing, it was devastating'

Parents were then asked to consider what they now think would have retrospectively helped them. (n=38) responded to this question and their answers covered four themes: non-specialist responses; access to support, time, communication and information.

Non-specialist responses

Ensuring the non-specialist medical professionals managed the situation with sensitivity and care:

"It would have made it so much less stressful if the local hospital that was dealing with us first had more knowledge of these conditions and also, most importantly even, how to deal with parents in this situation in a reassuring and calming way."

Access and signposting to support

Some parents reflected that being able to meet other parents or an adult with a similar condition soon after their child was diagnosed would have made a difference to their experience.

"It would have been useful to talk with other parents of a child (or an adult) who had a similar level of condition. We have found the hypospadias support that exists online then and now, too narrow to include the more extreme cases and conditions"

"Not having the initial conversation on an open ward where everyone could hear!"

"To talk with someone who's going through the same as you, understands the frustrations of the early days and doctors not giving you much information and ask..... have you asked the doctors this, did you understand this or have you thought of it this way and it's Ok to feel angry and upset was THE most helpful thing for me."

Other parents felt there was a role for healthcare professionals in a support role such as 'a dedicated nurse' or 'advocate'. Psychological support was mentioned a number of times, both in the context of when diagnosis was at birth and those diagnosed in childhood.

"More psychological help as this was a lot to take in as the condition was diagnosed at birth and not during pregnancy."

"Information about condition; psychology support for our child"

Time

Time was referred to in multiple contexts. The time it took to get a diagnosis for their child and the time it took to be referred to the specialist centres.

"[What would have helped would have been] being transferred to a hospital that specialised in the condition, be given information on treatment etc"

Not to be rushed and given the time to be listened to.

"To have someone sit down and really explain things so I fully understood. Not just tried to fit it in a 10 minute appointment." And time to process, particularly relating to the decision making timetable and how much pressure parents felt from this:

Not to be rushed and given the time to be listened to.

"To have someone sit down and really explain things so I fully understood. Not just tried to fit it in a 10 minute appointment."

And time to process, particularly relating to the decision making timetable and how much pressure parents felt from this:

"A less stringent timetable for surgical decisions"

"[What would have helped would have been] being transferred to a hospital that specialised in the condition, be given information on treatment etc"

“The doctors jumped to conclusions on what we wanted for our child. This made the process much more stressful. I would have preferred if the doctors spoke to me about our views on his treatment before booking us in for tests.”

Information and communication

“They told us to try not to Google things as there’s quite a lot of misinformation out there and it may not help until we had a firm diagnosis. This was like telling us your life is completely changed from this point on but we’re not going to tell you very much about it just now and don’t try and understand it anymore by your own research either, just wait for a confirmed diagnosis.

Of course I went straight home and Googled the term AIS and found a few more bits of information, some positive and encouraging and some scary and upsetting but all of it very helpful to me. I NEEDED to try and understand what was happening and the lack of any kind of real information was extremely difficult for us.”

Many parents talked about the information, conversations and signposting they would have liked to received. Some referred to how they would have benefitted from being given information to take home and how this would have supported and reassured them.

“INFORMATION! I can’t stress enough how difficult the first few days were for us. We were told a huge bombshell...were given some vague potential outcomes and a potential diagnosis of AIS and sent home with no leaflets or resources what so ever. I literally had a scrap of paper from my bag which I’d managed to scribble down a few terms. My husband didn’t attend the initial meeting as we had no idea they were going to tell us something like this so trying to explain everything to him...was very hard.”

Support and information you have access to now

"We have 6-9 monthly consultant appointments. Most of them in the first year were only with us and not our daughter so we could try to understand the condition and get a confirmed diagnosis. We were told all the possible conditions and brief details on what that might mean for our daughter.....I did my own research into all of these so I could understand what was or might happen. We were also offered specialist physiological support at first which did help in the early stages for me."

The survey then asked respondents to consider the support and information they get now and whether they feel this is the 'right amount'. All 47 answered this question, with (n=31) saying 'yes' and (n=16) saying 'no'.

Those who answered 'yes' were asked to list what support and information has been available and useful. (n=32) listed their experiences and these fell into two themes: Healthcare providers and community support and information.

Healthcare providers

"We have found the support and information offered by a range of NHS services extremely good, including paediatrics, surgical, urology, endocrinology etc. Recently we have been referred to the psychology services, which we have found to be superb and have quickly realised how much we needed them without knowing."

Many parents who had access to specialist psychological support spoke of how this was a huge benefit to them.

"Our psychologist was a rock. She would see us whenever we wanted and gave us, as parents all the information she could. She was so

understanding and her advice to both our children, who asked for help in their development and other issues surrounding their behaviours was invaluable."

Parents mentioned on-going support from clinical staff with regular appointments was a real source of support, information and comfort:

"I know I can go back to my consultant with questions if needing. She is guiding us to a clinic for teenagers as a stepping stone to adult care."

As was knowing that the healthcare team are accessible and will respond quickly,

"...message left on answering machine and next day response from nurses."

Community support and information

The other area mentioned was that of the community organisations that provide information, Facebook groups and support:

"Other parents. Experiences. List of resources as child ages such a Pipo and Pepo or the amazing Sophie."

"...Finding out about the CAH support group & forum also helped us massively - [They] are a mine of information & absolute stars: they help support us emotionally & the hospital do the physical bit. We would not feel as supported without the group. Newsletter from support group is also brilliant."

"AISdsd.com"

"Being in touch with other families through the DSD website. Knowing we could email questions or discuss how we are feeling and know that no matter what, we are fully supported but it is only through the website. The medical team talk a good talk but change their mind."

One parent did say in this section that although they had got enough support and information, that this was something they had to find, rather than it being signposted to, *'you definitely have to ask for it or look for it yourself.'*

Those who said 'no' they did not get enough support were asked what would be useful for them. (n=17) replied and their responses fell into a number of themes.

I still feel a bit lost sometimes. We have now got a diagnosis which is good but when things start happening with your child around puberty for example you need to be able to ask questions more frequently than the consultant appointments allow. We were told she'd never develop breasts or pubic hair yet she has both of these things. How is that happening and what does it mean?

Talking to your child about their condition

Some parents wanted support and information on how to have conversations with their children and make sure they are well informed in non-stigmatising way:

"We need support and help in having conversations with our child with regards to their diagnoses and how to navigate through this day to day and in the future."

Some of the parents focused on the psychological and peer support they would like to have:

"[We want] to have more psychological support for the parents; more opportunities for regular meetings with other parents that would be led by medical professionals and psychologists at least on some occasions..."

"A support group, people to talk to regarding adulthood for my daughter and negotiating adult services"

In contrast to those parents who felt supported by their healthcare team, others felt the opposite.

"I have no support. No counselling. No psychologist for Me or my family, I have called several times, I've just been told come back when she starts puberty and I will have to be referred back"

Feeling that the healthcare team was 'inaccessible' was a common theme in this group.

"I don't always feel fully supported by our hospital. If I have a query we have to wait until our next clinic appointment- up to 12 weeks."

These positive and negative experiences highlight discrepancies in what is offered to families both in the healthcare setting - support staff, psychological services, regular appointments and access to healthcare providers even if the child at that point has no healthcare needs – and the sign-posting, or lack of, to community organisations.

Information and support in the future

We will need psychological support; we will also need the help from the specialists that we've seen since our child has been little - such as endocrinologists, urologists and gynaecologists when our child is a teen. We would need to have built a network to of other families like us for the kids and the parents to support each other.

Parents were then asked to reflect on what support and information they think they might need in the future. All 47 responded to this. 'Support' was by far the biggest issue raised, with peer support groups, Family Days and learning events by far the most popular responses from parents.

"Meeting other families with similar issues, so far, has been comforting and helpful from a parental perspective. Allowing our children to talk freely together and being able to talk freely together has been liberating, it would be lovely to have it more often."

"We attended a CAH conference a few years ago at the hospital - more days like this would be great. Meeting other parents of children with CAH. We still want an 'epi-pen' style emergency injection!"

Many parents mentioned the importance of such events for their children, in building resilience and peer networks.

"I love the sound of family get togethers - more than anything I want my son to easily connect with others who were born like him so he doesn't feel alone or isolated."

"...Make her feel she is not the only person with this genetic condition by meeting other families at least once or twice a year"

"Peer support is vital for both parents and the children - my daughter is desperate to meet others like herself."

Other parents wrote about the emotional support they want in the future from peers and professionals for themselves and their children.

"Mostly emotional support. She will never have children without help and that is going to be hard to explain one day and also how much she needs to keep on top of her health."

"On-going emotional and psychological support and to meet with others"



Transition support

Some parents shared their concerns about their child leaving paediatric services; what care they could expect from adult services and whether there would be clear transition pathways.

"Help with move into adult care and allowing them and empowering them to take control of own condition and management."

"To know that my child will be looked after just as well when she is an adult."

Where information was highlighted, there was primarily a specific focus on puberty and how to talk to children at different stages to ensure their knowledge and build their resilience.

Clear, detailed information

We are now approaching the age at which our child will start to become aware of their own body and also will receive sex education at school. Soon we will begin to discuss and make them aware of their condition. Although there is some information with regard to how best to approach this available online, it would be useful to have more (including case studies) and covering a much broader spectrum which may include our more extreme condition.

Where information was highlighted, there was primarily a specific focus on puberty and how to talk to children at different stages to ensure their knowledge and build their resilience.

“Clear and detailed information in printed form that I can digest and re-refer to as needed.”

“Moving into teenage years, how to raise child with confidence and support them to develop self-esteem and strong identity. How to develop independence with them and how they can manage their own medication and treatment. Support and information around surgery, best time, where and who does it?”

Parents wanted information to be clear, accessible and in an age appropriate formats for their children.

“...He talks of getting married and having kids of his own... as he is infertile at some point he is going to have to understand this is not possible on all aspects...”

“Child friendly information leaflets to be given at a very young age to explain the condition, looking after yourself, treatment etc”

Working together with health

Some parents expressed how they wanted to develop their relationship with their child's healthcare providers in the future. They expressed the desire to work as a team, which included healthcare providers sharing unknown outcomes with parents.

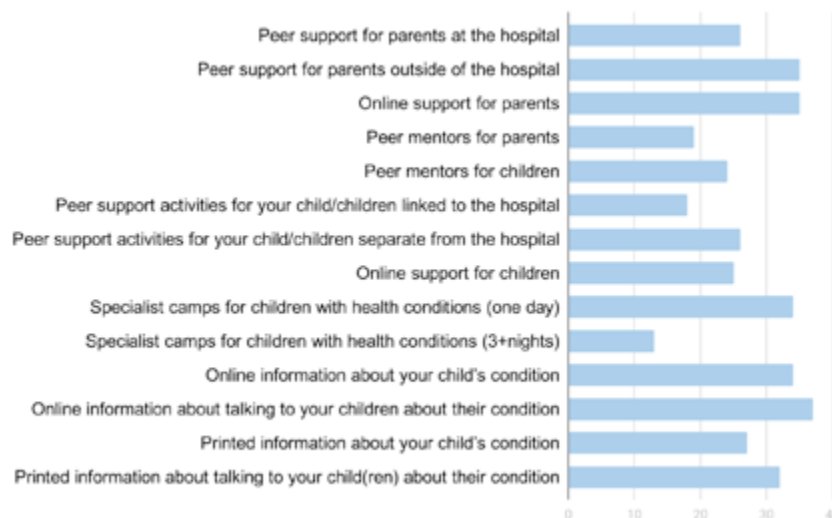
“Expected outcomes. Knowing what to expect is helpful so long as this is caveated with a ‘things might happen this way but it might not.’ I’m learning that with DSDs things are often very unclear and don’t always progress how the doctors think. Withholding any information at all though is far worse.”

“Consistent information. Our daughter’s Dr keeps changing his mind about how best to proceed. How best to discuss things with our daughter.”

“[Conversations with] specialists who might have a knowledge of the difficulty rather than feeling you are in no man’s land. When I raised the question of mental health etc. I was told that there was not a problem just what parents imagined! Later they did research into this with younger children. My child was overdosed with steroids which has had long-term disastrous effects.”

Parents were then offered a number of types of support they might like to access and asked to choose those they would be interested in. All (n=47) completed this and Table 6 sets out their responses.

Table 6. What support would you be interested in accessing?



We believe that successful peer support could be critical to how our child manages their condition in the future. Even though we find case studies (usually with pseudonyms) very useful, they are often not exactly relevant to our condition and there is little or no way to start a conversation with the contributor. Therefore, we feel community and support forums would be very helpful, however we recognise like us, many people may not feel comfortable to be identified. So they would need to be anonymous, to a group of approved account holders, so to allow full and frank conversations.

Additional comments

The final section of the questionnaire gave the opportunity to add additional comments. (n=24) filled in this sections and their comments fell under 3 themes: Thank you, healthcare provision and public awareness.

'Thank you'

Mainly thanking dsdfamilies for setting out to do this work and giving families an opportunity to share their experiences and their hope that this would affect change.

"Thank you for the funding to create and hopefully maintain the support needed for these children. Hopefully education and research will help in the future"

Some left comments of gratitude and acknowledgement for the work undertaken by the charity already and its impact on them personally.

"Without dsdfamilies I would feel lost. When we first were told about our daughter's condition we were given A LOT of medical terms and a lot of verbal information we were expected to remember. I am so grateful to have you guys running the website to rely on. So from the bottom of my heart THANK YOU for all you do."

Healthcare provision

The main issue reiterated in this section related to the desire and need access to clinical psychologists for parents and their children.

"Our child was referred to three psychologists for support, all three refused to work with her. All saying it was not their area of expertise."

We had to wait nearly ten months for a psychologist to accept to work with our child, we are yet to see a psychologist”

The difference in the care provided to families was raised again, with one parent asking for:

“Standardised care: I would like to see greater standardisation of support and care throughout UK”

Some took this as an opportunity to just reiterate issues already raised in the survey such as the transition to adult care, including adult care itself:

“The transition from child health care to adults had been very difficult and there’s little out there for adults in a specialist service format.”

Public awareness

A few parents used this section to raise the issue of lack of public awareness and how important it is to address this.

“There is not enough information about CAH [in the public] and there are lots of adverts for cancer children and what money we can donate I think the same should be done for our children as I have two with CAH and when I talk to people about it they look blank as they don’t even know what it is or heard of it.”



All of the above would be fantastic - information and support is hugely lacking at present. Also I couldn't have got through the first weeks and months without the advice, support and friendly ear from [founder of dsdfamilies and parent]. I was frustrated, scared and almost completely in the dark as to what was likely to happen in the coming weeks, months and years and she really helped me understand the medical system, reassured me things wouldn't be as bad as I feared, talked about her own child and experiences and I cannot say thank-you enough. I hope the website continues to improve as it's not easy to find or navigate but the resources contained are vital. Would be great if doctors would tell families about this fantastic resource very early on. Thank-you

Consultation Activity: Family Days

In total 52 parents and caregivers attended the three Family Days. At each event the parent group discussion lasted for over two hours and was dynamic and lively. The parents varied from those with newborns through to those with children who were teenagers and young adults. The discussions across the family days are covered in five core themes:

- Experiences in the health system
- The experience of being a parent of a child with different sex development
- Talking to and supporting a child with different sex development
- Schools
- Society

Throughout the discussions, where issues were raised, parents were asked to suggest solutions that would have helped or might help in the future. These are included as 'parents recommendations' under each theme. There was one overarching recommendation from all the meetings which was 'we need a voice'.

THEME ONE: Experiences in the health system

These discussions fell into two sub-categories, that of the experiences in non-specialist health services and the experiences in specialist health services.

Lack of knowledge and information in non-specialist health services

Parents spoke about the period of time just after their child's birth and how they were left with a lot of anxiety and feeling like "...we had been left in the dark". Some parents shared how non-specialists had made comments to parents that caused them distress and felt like there was a lack of understanding of what the parents were going through.

Many of the parents shared the experience of having to wait for days or weeks to have the condition explained to them. One mother said that she spent days worrying whether her child was seriously unwell after being told “the test was positive”, but not what the test was for. She was actually relieved when the condition was explained to her.

This was seen as a ‘scary time’, and many felt they lost out on the first few weeks of their baby’s life, a time they could never get back.

“There are pictures on Facebook with one baby in blue and the other in pink. She then got re-assigned as a girl. But those pictures are still there”

Parents also spoke about their experiences in non-Specialist services as their child was growing up. One parent told the story of coming from a small town and going to their local hospital about something non-related and being told: “Oh you’re that family – we’ve all been talking about you.”

Where children have CAH, parents reported the additional worry of late diagnosis and the baby failing to thrive or becoming critical ill, and how this impacts on the whole family. Where parents knew their baby’s sex and CAH diagnosis prior to delivery, some spoke of how the inpatient medical service breached their confidentiality by alluding to being unable to sex their child in the presence of patients on a hospital ward. There was no offer of a private room for this private conversation.

The lack of knowledge and understanding in non-specialist medical services and the impact of this was very clear from the experiences shared.

Experiences in specialist health services

“Why is there inconsistency in care and what happens around the country – people tell us what we have is different, why is it not the same everywhere?”

Through discussions, it became apparent that there are inconsistencies in the clinical care and support provided at different hospitals across the UK. For example, parents spoke at length about their own and their child’s need for psychological support. Some had access to a specialist clinical psychologists, whereas others said they had never been offered this service.

Parents shared the different ways they had been explained their child’s diagnosis. Some spoke of ‘support’, ‘clear, simple explanations’, whereas others felt ‘abandoned’.

“I just got a letter with my son’s diagnosis. That was it. A letter. I needed someone to talk to, to talk to me.”

Some parents spoke of receiving their child’s diagnosis and being told to ‘come back when they reach puberty’. Others shared how, even though their child has no clinical needs, they still are offered regular contact with the clinical team. They said this was ‘reassuring’ and meant they were able to ask questions.

Through these discussions parents expressed concern that the treatment pathway felt dependent on the perspectives of different clinicians at different hospitals, rather than an agreed standard.

“I still don’t understand what’s going on”

Medical appointments were an issue for some parents. Some spoke of too many appointments and the child was missing school or parents missing work. Others spoke of high levels of anxiety and concern due to long periods of time with no contact with the medical team.

Some parents’ spoke about the genetic counselling that was provided for them, and how it made them feel like they “shouldn’t want to have another child with CAH”. Others spoke about how IVF and abortion were given as options. A few shared how they found the genetic counselling was ‘patronising’ and a “due diligence” exercise .

It was clear that experiences were really varied and that this variation was not necessarily due to different health conditions, but more that what was no national consistency of the care being offered.

The lack of psychologists seemed to be a central theme, as the families where a child had no health needs often had their regular clinical contact (even if only once or twice a year) with a psychologist. Here the families understanding and emotional needs were seen as part of the clinical care offered.

Parent Recommendations

- A nationally agreed protocol for minimum annual contact with the medical teams, even where there are no medical needs. This will give families the opportunity to ask questions and be given information.
- All families have access to a clinical psychologist, particularly at the point of diagnosis, but also available at critical points in the child’s development
- Understanding from medical profession. Parents want to be asked:
 - ‘How are you?’

- 'Do you have any questions?'
- 'How do you feel about the future?'
- 'Would you or your child benefit from psychosocial input?'
- Drip feeding information to parents to make sure they understand it and have taken it in.
- That medical professionals are aware of all the different resources and organisations that can help parents and signpost parents to them
- The UK needs to screen for CAH.

THEME TWO: The experience of being a parent of a child with a different sex development

"I want to do anything I can to help. To make sure no-one has to have the experience we had"

The parents spoke of the different aspects of parenting a child growing up with different sex development, from the point of diagnosis, the support they needed, who they should tell, what they should tell and talking to their child(ren).

Point of diagnosis

There was a shared feeling of 'shock' and for some 'trauma'. They spoke about how the responses of medical staff impacted upon this.

"We went to the ward and then a junior doctor said: 'you might not want to announce the birth of your child". That really rocked us"

As mentioned before, the lack of communication caused parents a lot of anxiety.

"[We had] no support of any kind for the first 4 days. [We needed] someone to say what sorts of things they were looking for and why. What is the reason that they would not tell us anything?"

Some parents spoke of the feeling of 'loss' and the 'grieving process' they went through, whether it was for a child of a different gender, fertility concerns or the 'lost time' in the newborn period when they were going through diagnosis.

"It ruins the newborn period. You don't ever get that time back"

Peer support

“We need a community – we need to meet other families”

Many parents spoke of feeling isolated in their experiences, both psychologically and geographically. Some parents had met others before, but for many the Family Day was the first opportunity they had had to meet others.

Parents spoke about being unaware of other families in the area going through the same thing. At one Family Day, two parents commented on how they had sat in the waiting room at the clinic together the day before and not looked at each other. Those that have had the opportunity to meet other families spoke of how this alleviated that sense of ‘isolation’.

At all the Family Days, there was a consensus that peer support would be ‘invaluable’. Different possible issues were discussed, such as how peer support with other parents should be offered on more than one occasion as parents might not initially be ready to engage. Some parents felt that ‘pairing with another parent who has been through it’ at the point of diagnosis would have had significant value, even if this was just a conversation via SKYPE.

“[It is] helpful to see pictures and hear stories of other children with the condition having fun and an ordinary life”

It was mentioned that some families had been paired together through the organisation Living with CAH. Others spoke of how this pairing was offered by the endocrine nurse at one hospital. All felt that access to some kind of peer support would have made a significant difference to them.

There was agreement that if peer support was not available, then support from experienced professionals such as specialist nurses and psychologists was essential.

It is important to note the distance some families travelled to attend the Family Days, for example from Scotland to attend the North West meeting, and from London and Birmingham to attend the Bristol meeting.

“[It] helps being together, I prefer to talk in a room like this, not to friends and family”

Sharing a child's health condition

"I feel I want to share, but it needs to be in our daughter's best interests. It's her information"

There were discussions on how much information about the child's condition should be shared with extended family and the community. There was a lot of fear of prejudice from the wider community, including fear of how other children might respond to their child, 'Kids are cruel!'

Many talked about how the diagnosis was not theirs to share, *"It's not my condition to tell people about"*. And how the process of sharing was not something you could then retract, *"You can't take that that back once it's out there"*.

Where the child had no other medical complications, some parents felt that there was "no need" to share this information with anyone else.

But parents acknowledged in their discussions that by not speaking about it, they do not get support from wider family and there is no understanding in the community.

"[We] cannot open up to family and friends –they might push you away and feel ashamed. [We] want to be able to talk, but are unable to"

Some parents said they were open with close friends and family, but tell no one in the wider community. One parent shared having a transgender relative currently in transition and this was shared with everyone in their wider family. That parent felt it was because 'this was now socially acceptable', whereas differences of sex development still needs to be 'kept secret'.

Where the child has CAH, elements of their health condition should be shared due to possible need for emergency treatment. Parents discussed what they did share this, but feared people Googling the condition 'and seeing the other things about her'.

Medicine

Where a condition requires regular medicine, many parents reported finding it difficult to leave their children with anyone else due to the responsibilities. Some parents said that they could not leave their children with family because "nobody wants them, nobody wants the responsibility". One mother said that in 7 years she had only had a handful of nights away from their daughter.

It is clear that there are many shared experiences amongst parents relating to raising a child with differences of sex development. There can be high levels of anxiety; the feeling of being unable to share the information and get the support needed and the desire to protect the child from negative responses. All these are perfectly normal parental responses, but can impact on family relationships and the child having access to activities we would expect them to engage in such as sleep overs, time away with other family members etc.

Parents Recommendations

- Psychological support to be available, both to the parents and children.
- Parents need groups and to be able to be integrated into them early on.
- One suggestion was, as with adoption, organ donation etc, parents should be asked if they would be happy to speak with another parent with a newly diagnosed child with a similar condition. If the parent agreed, then healthcare providers could pair up parents.
- A structured peer mentor programme, where mentors have training and supervision. This role would primarily be as a link person in the first few weeks of diagnosis, either in person, a call or via SKYPE. "We just need someone to say, 'it's going to be fine'
- Parents should be offered peer support a number of times. They may not want this support initially, but circumstances change and they could change their mind and decide they would now value this peer support.
- Leaflets or an App to help us explain this to our friends and family.
- Good online information that is widely promoted so all families know about it. This should include current research findings and the latest science, set out in lay terms. The website could also offer webinars on specific topics, with experts speaking and the facility to ask questions and access these webinars after the event.

THEME THREE: Talking to and supporting a child with different sex development

"[We] need to build resilience in our kids. Our kids will hear bad stories – they are all over the Internet – we need to prepare them for this and make sure they hear good stories too"

Parents spoke about talking to their child about their health condition and the different experiences they have had, or not had, doing this. Some shared that they had always been open with their child, others felt they wanted to wait and some felt did not know how to have these conversations.

"I haven't got there in telling my child, I'm not sure how to do it".

Particular issues that came up in these discussions were feeling unable to answer their child's questions and give accurate and comprehensive information. Parents were clear that they wanted their children to have a good understanding about their own health, particularly before they got to an age where they might start seeking information via the Internet.

As some conditions are hereditary, some parents had concerns about broaching the subject with their other children and their extended family. They worried about how other family members might react to the information, "[I] don't want to be judged".

Many parents spoke of the struggle of finding a balance between 'privacy', protecting a child and not stigmatising the child through 'secrecy'. They spoke of how, by not talking about it, this gave the child a message that their health condition was something 'shameful'. But at the same time they felt by not talking to the child about their health condition, this would 'protect' the child.

"We tell our children 'don't tell anybody', but what is the message we are giving them by this? We are adding to it."

Puberty and adolescence

"We need to have the confidence to talk to our children"

There were a number of issues that parents spoke about relating to their children's journey through puberty and adolescence. Some parents felt ill equipped to have conversations and answer questions relating to anatomy and making their child aware that they were on a different path to some of their peers. They spoke about wanting to be able to have these conversations, and be able to give their child the language to answer questions when other people asked them, such as future partners and friends.

"We need to make our children the experts on themselves"

There were concerns over transition to adult healthcare services and how well the child and parent may be prepared and cope with this.

Parents acknowledged that their child needs support outside of the family. They spoke of groups, more Family Days and older young people working as mentors. Some were keen to have 'camps like diabetes do'.

They spoke about the information needs of their children, and how these should be dynamic and interactive, using 'videos, podcasts and online information'. Some suggested these should include the experiences of older young people with differences of sex development:

"[Information for our children should include] How I told my boyfriend/girlfriend, my coping techniques, challenges and what I'm doing now."

They felt lots of topics should be covered, but wanted a strong focus around sex, sexuality and relationships:

"Our children need information and advice – sex ed at school won't cover this, there will be differences for them and they need to know these"

"[They need] positive messages – that it's OK to have sex"

They felt advice from young adults on how to deal with 'risky' or 'dangerous' situations (examples from parents included drinking and sex) would be really helpful.

Many parents said they would want to have all these conversations with their children too – about their health, anatomy, sex and relationships - but they 'just don't know how.'

"Tell us how to approach this, what language to use"



Parents Recommendations

- Peer support for children and young people, such as family days, camps and activities to bring the children together.
- Older mentors for children with the same or similar conditions.
- Books/leaflets around puberty and sex for different ages, like the books already out there, but specific to different sex development conditions.
- Online age appropriate information on each condition, puberty and sex.

THEME FOUR: Schools

There were two particular issues that arose relating to schools: (1) sex and relationship education and how biological 'norms' are taught and (2) children with CAH that may need emergency medication at school.

One parent shared how her child had been upset at school by the content in biology and PSHE lessons around '*anatomy and gender*'. Other parents voiced concerns about this too. It was felt that there needs to be awareness raising of difference in sex development amongst teaching staff and in the national curriculum for schools so this can be covered in a sensitive way.

Many mentioned how having periods is an inevitable part of a girl's adolescence and is seen as '*normal*' when spoken about by teachers and amongst friends. They were anxious that this would make their child feel '*different*'. There were a few cases of children '*being teased*' for '*looking different*', and parents felt schools should be addressing this and educating children to accept others.

Regarding CAH and emergency treatment for children, there is currently an irregularity between the level of support schools provide. This was a topic that arose in all family days amongst families with children with CAH.

Parents spoke of feeling "*filled with fears*" due to this change in practice. At different Family Days parents spoke of feeling home schooling was the only way to '*keep our child safe*'. One family were considering moving close to the school so they could '*rush there*' should an emergency arise. Parents spoke about children starting school later because the issue of the injection could not be resolved.

Parents were visibly distressed by idea of school staff calling an ambulance and waiting, rather than giving an emergency injection. It was apparent parents believe their children is at significant risk in school while teachers are not trained to give an emergency injection.

Parents Recommendations

- Schools need guidance and protocols regarding SRE and lessons relating to puberty and physiology.
- The current situation where children with CAH are not being provided with the facility to access to emergency injections needs to be addressed urgently.

THEME FIVE: Society

“No-one knows anything, so there are no challenges, other than the challenge to keep this all to yourself”.

The final theme raised in the discussion with parents at the Family Days was that of the wider community and society.

“Gender is a big issue now. Intersex is not understood”

Parents spoke of the lack of knowledge and understanding in the wider community and how ‘people don’t get it’. Parents shared how the impact of this can lead to ‘isolation’ and not getting the support and understanding ‘that families need’.

When talking about the public sphere, there was more discussion around the dilemma between this being private information, so not wanting to share it, and feeling unable to share it even if you want to. There was universal agreement that there is no public awareness around the different conditions and that addressing this could have a significant impact, especially as culturally there is now much more open discussion around other ‘taboo’ areas such as gender identity and sexuality.

PARENTS RECOMMENDATIONS

- Greater awareness through factual media coverage to educate people and raise the issues.
- Specifically some parents would like to see a change in birth registration so this can be done without the sex of a child being stated.

Conclusion

A child’s health condition can impact on the whole family, and this was demonstrated clearly in this process of consulting parents. There are Standards of Care (referenced in the recommendations) but parents were unaware of these and their discussions highlighted the need for these to be reviewed and implemented nationally to ensure every child receives the optimum care, which includes psychological and emotional care.

Parents need support. This support could come from their peers, professionals and from their families and communities. To achieve this, there initially needs to be an increase in support available, more information for parents on how to explain things to their families and an increased awareness of these issues nationally.

Parents also want support for their children, so they can meet others and not feel they are the only one having the experience of growing up with different sex development.

There is a need for detailed, clear, understandable information available for parents and for children, in multiple formats, that will ensure knowledge, understanding and build resilience in families.

The discussion on schools not providing injections where a child is having an adrenal crisis highlights how the change in practice and why it has happened has not been adequately explained to parents.

Message sent after Family Day:

“Thank you! We are so glad we came to Bristol it was really helpful to our family and we exchanged telephone numbers with other families with the same condition and we have set up a WhatsApp group and we talk regularly, so thank you”

6. FINDINGS: ADULTS REFLECTING ON THEIR EXPERIENCES AS CHILDREN

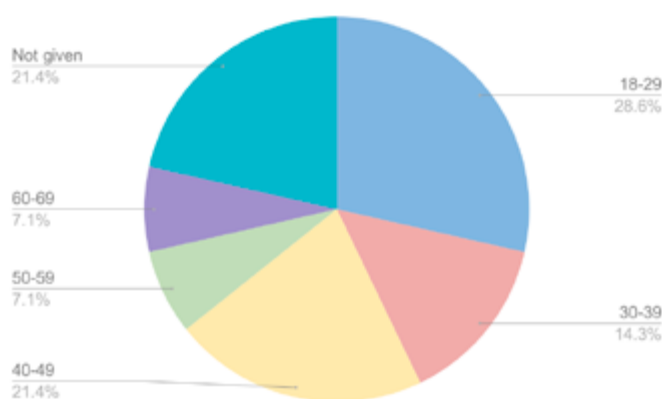
“I would have liked to be informed of the nature of my condition & the possible consequences for my subsequent development. Some staged therapy throughout my childhood & adolescence would have undoubtedly helped with my self-acceptance & self esteem. If I am honest I feel let down by a system that should have cared for not only my physical but psychological needs” Aged 47

It was felt important to try to capture the experiences of those who are no longer children and have lived their lives with difference of sex development. Therefore, there was an additional online questionnaire specifically for adults (18 years and over) to provide an insight from them. Their ages have been included with direct quotes as some answers may indicate out-dated practice.

Consultation activity: Online and paper questionnaires

14 responses were received to this questionnaire and Table 7 shows their age breakdown.

Table 7. Age breakdown of responses to adult questionnaire



Of those that responded (n= 3) were from the South West, (n=2) Wales, (n=2) the Northern England and Yorkshire and (n=2) Eastern. There was (n=1) each from the North West, the Midlands and London.

Being told

When asked how their health condition was explained to them, (n=11) responded, covering a ranged of very different memories and experiences, both negative and positive:

“My mother told me I had had 3 surgeries for a hypospadias, she was unaware that it was a DSD or may have any subsequent impact on my sexuality or gender. I then confronted my Doctor having found information on the ISNA website who then confirmed that I had had a penoscrotal hypospadias”. Aged 47

“Euphemism & lies” Aged 27

*“I was told I would not get pregnant naturally and that was it for many years, until I started pushing for more tests and explanations”
Told at 14, aged 23*

“[I was told] you don’t have enough testosterone, we’ll replace it and you’ll be fine (not).”Aged 40

“Bit hard to say. I had it since birth so it was a gradual realisation and explanation over time, rather than a sit-down “this is what you’ve got”. I grew up knowing no different and gradually became aware, I guess, as I went to school and noticed that I was going into hospital lots unlike other children” Aged 40

“Clearly, with sympathy at the hospital” Aged 29

The information received

When asked about the information they received as children on their health condition, all but one said they ‘would have liked to have known more’. They were then asked, what information would they have liked to have had. The responses were all similar and referred to how there was ‘nothing’, particularly relating to the realities of the emotional and psychological experiences they had.

“Anything, leaflets, counselling, support group access” Aged 40

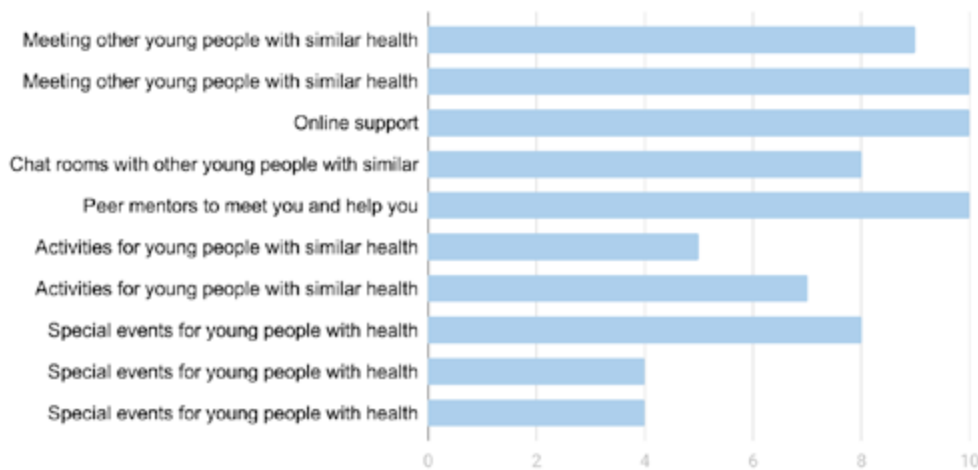
“The subject is huge, so as much information as possible. I think the ‘scientific’ part of the condition gets covered by doctors a lot (I’ve been drawn a diagram so many times to explain my condition) but the practical realities of the condition need to be explored and discussed much much more I believe.” Aged 31

Meeting others

Respondents were asked about whether they had ever met someone else who shared their health condition, (n=10) said they had and (n=4) said they had not. They were then asked as a child, would they have liked to have met someone with a similar or the same health condition. All (n=14) replied ‘Yes’.

In line with the questions asked in the young people’s survey, they were then asked to specify what sort of peer support might have interested them as a child. Table 8 shows their responses to a list of multiple options.

Table 8. Support you would have liked to access as a child



Finally there was an open section where respondents could leave any additional comments. (N=9) completed this section and many left powerful messages relating to their own experiences and encouraging learning from these.

“My penoscrotal hypospadias & the implications regarding my sexuality & sense of gender is something that I still struggle to come to terms with at 47. I just wish there had been a much more open & honest climate to grow

up in, the secrecy (& by implication shame) & ignorance around the condition is what has caused for me the most damage.” Aged 47

*“The shame that is associated to this condition is really difficult to live with”
Aged 23*



“ ...I was a sociable child so meeting other children with same condition would have been great. Things have changed so much now, which is wonderful. I didn't meet anyone else with my condition until I was in my 40s and have never had the opportunity to find out the real truth about early and later surgeries which has had a traumatic impact on my life. I think early surgeries should be stopped

unless it is an urgent medical need. I don't like the term DSD as this has negative connotations linking with the medical 'Disorders of sexual development'. Personally I think variations of sex characteristics is a much better term.” Aged 55

“ ...My main point is around inclusion - there's SO much stigma, ignorance and misunderstanding around people with a DSD. More work needs to be done in society/education to increase the tolerance and acceptance of these largely congenital conditions. Thank you. I hope your research makes a positive difference!” Aged 40

Conclusion

This small group of adults offers an insight into the lived experiences of people growing up with differences of sex development (or variations of sex characteristics). Asking them to reflect back on their childhood, even in this small way, can support a better understanding of how we can improve the experiences of children growing up today.

The need for information and support has not changed greatly and the answers given here reflect the answers given by the young people and their parents. This group also offers an insight into the impact in adulthood of differences of sex development, and how support and information in childhood can build understanding and resilience that could have significant impact for the rest of that person's life.



7. THE EXPERIENCES AND VIEWS OF PROFESSIONALS

During the consultation process we have spoken, both formally and informally, with various professionals from healthcare and academic backgrounds. Many have shared their perspective on the issues families face and the support and information they think could benefit them. Some of the healthcare providers we spoke with have looked after hundreds of children, young people and their families over many years.

Support

It was acknowledged that all people are different and will have different support needs, and to this end, there needs to be various options offers. There is currently a lack of peer support available, and it was also noted that some support groups that previously existed are no longer operational.

Most professionals felt that:

- The opportunity to access peer support would be hugely beneficial for many children, young people and their families.
- The care and support provided regularly from the multidisciplinary team was essential, and many commented on how NHS cutbacks had led to a decrease in the number of psychologists. It was felt this was having a significant impact on families.
- Access to one-to-one support via the internet would help some people

Areas highlighted where particular support or information would be needed included:

- Adjusting to parenting a child with a difference of sex development
- Understanding differences of sex development
- Managing relationships with the medical team
- Decision-making about treatment
- Supporting their child with treatment
- Talking to their child about their difference of sex development
- Talking to others about differences of sex development (e.g. family, school)
- Differences of sex development /intersex advocacy and identity

Through the different discussions there were some clear priorities raised

Peer support opportunities

That all parents have the opportunity to be in touch with or meet other parents. It was hoped that if parents access this initially, then they would encourage their children to meet other children in the future.

Wider knowledge

This covered two areas, increasing the wider knowledge about differences of sex development amongst non-specialist medical staff and finding ways to remove the stigma of differences of sex development by raising awareness in wider society.

“Families need to have someone to listen to them and who has time to listen, who has time to help and co-ordinate their care in whatever direction they need”.

Psychological support for all families

The lack of experienced specialist psychology support nationally was highlighted as an issue. The benefits for parents and children and the need to try to address this was acknowledged.

Newborns

A comprehensive baby book about different sex development and/or genital difference for new parents.

This could be one resource covering all differences of sex development, or shorter versions for each condition. Areas it should cover are:

- Simple biology
- Explain why this has happened
- How to care for your child (if there are any differences)
- The care pathway families can expect
- What happens now
- What the future might bring
- Signposting to organisations, resources and support (if there is any)

(This could include further developing the dsdfamilies resource: ‘When your baby is born with genitals that look different - the first days’)

Children under 12s

In some ways similar to the above, but with each condition needing information and resources. This would be a set of resources with further explanations for parents and age appropriate children’s versions. The content should include:

- Simple biology and what might happen in puberty
- What families should expect from their healthcare providers (care pathway)
- Dealing with playgroup, nursery
- Growing up and puberty
- Easy, child-friendly leaflets parents can use to talk to children

Young people 13-18 (or from 11-18)

It was felt that information should be available for parents; for parents to use with their child; and for the young people to look at independently. Again, this would cover similar areas as the above resources and all should link up and be ‘building blocks’ of information:

- Simple biology
- What to expect from health (care pathway)
- Why did it happen
- How common is it

- What does it mean to me
- What support is there
- What treatment is there (and what will this do and be like)
- How do I meet other young people like me?
- Useful websites
- Integrating into adulthood - sex and relationships, fertility, transition to adult services (and what to expect there)

Conclusion

As the above shows, so much of what has been said by young people, parents and adults is reflected in the conversations with professionals. Amongst the professionals that engaged with this consultation, there is acute awareness of what is lacking for children and their families.



8. REFLECTIONS

The topic of infant surgery in relation to differences of sex development is often discussed in the media and public debate, but is not prominent in this report. This may be due to the specific focus of the consultation on 'information and support'. A different method of consultation may have opened discussions on and about surgery. All parents said they need better information, better support and help to know what to say to their children. These things are directly relevant to decisions about all aspects of care, including surgery.

This report is written in the context of children's rights. The consultation has underlined the need for the fundamental rights of the child to be placed at the centre of discussions about what best care means. Young people also talked about wanting to be better informed and involved in their healthcare from a young age.

Children and young people receiving healthcare often lack a voice. This can be due to the complexities of engaging children meaningfully in their own health care and navigating this with parents. A health condition that may carry societal stigma can further complicate this.



The consultations provoked a high level of anxiety for some parents, health care providers and children. Parents told us about their anxiety. Health care providers worried about our processes and were sometimes reluctant to involve families. Some children and young people were anxious at events so we worked to alleviate this before going ahead with discussion.

Reflecting on this together with our findings, increased information and support are undoubtedly needed. What we can learn from other poorly understood and/or stigmatised health conditions is that this is not just about raising public awareness, but also about current health care practice and whether this compounds fears of discrimination, or alleviates it for children and parents.

9. RECOMMENDATIONS

This consultation has offered a rich source of information and in this section we have highlighted some of the key recommendations that come from this. These recommendations cover multiple different areas and are for all those who are involved in or can influence the health and well-being of children with differences of sex development. This includes service providers, charities, healthcare providers and policy makers.

Involving young people and parents

Recommendation 1: This report recommends that dsdfamilies look to set up a 'Youth Committee' and a 'Parents Committee' who can influence the charity as it develops its portfolio of work. This will take time to develop, particularly the youth group, but over time will become invaluable. These groups will need a paid member of staff to support them administratively and to nurture and facilitate their participation.

Psychosocial support

Recommendation 2: The lack of expert psychologists has been a running theme throughout this consultation. This report recommends that dsdfamilies links with the British Psychological Society's Paediatric Psychology Network Special Interest Group for DSD and key clinicians to explore ways to address this. This could be through the charity applying for money to provide an Internet-based service, funding posts in hospital and/or lobbying Commissioners.

This report recommends that initially a variety of psychosocial support models be developed in partnership with healthcare professionals, for children, young people, and their parents. dsdfamilies should look to the experiences of other health conditions and replicated these models, including robust evaluations. It is recommended that this starts with pilot sites working with fully engaged clinical teams.

The key elements for psychosocial support should be:

- Offering learning and support for all who attend, regardless of age
- Youth groups run in partnership with youth workers to ensure the correct mixture of fun and activities that make learning fun and generate discussion
- Collaborating with the local/regional clinical team, supporting those running the group to undertake outreach with families to build relationships and increase engagement. This could be through establishing visiting NHS contracts, so charity staff can meet families in the hospital, build relationships and then feed them through to support groups.
- The groups or activities need to be seen as an extension of the child's care package and presented as such to families.

Peer Support

Recommendation 4: Peer support should be developed nationally. This could be a pilot parent peer mentor programme, following successful models such as the Mentoring & Befriending Foundation that has been adapted by other stigmatised health conditions. There could also be a small group of young people recruited who can work with charity staff and participate as facilitators and mentors when running youth activities. Both these aspects could then be developed as the charity's work develops.

Events

Recommendation 5: Key community groups, charities and professional networks come together to explore the idea of running a 'national conference for families', ideally fully funded or with bursary places available to ensure inclusion. There are similar models run in the USA that could be used to support the development of this. This could also take the model of a 'Family Weekender' run by Diabetes UK.

Collating and developing resources

Recommendation 6: A library or hub of existing resources are collated on the dsdfamilies website, and include clear signposting to other community groups online information and activities. This resource then needs to be promoted to clinical teams to ensure (in line with the Clinical Standards And Principles Of Management for DSD) all families are made aware of it and the different information and support available.

Part of collating this information hub will include making a comprehensive list of what information is missing (this report offers extensive guidance for this). It is then recommended that a 'steering group' or 'writing group' is commissioned to oversee the production of materials to fill these gaps. These should be in various formats - online, physical copies, videos etc – and should be produced using a 'by and for' approach, engaging the people they are targeted at, as well as medical and scientific endorsement.

Recommendation 7: dsdfamilies undertakes a review and overhaul of its current youth website www.dsdfamilies.org. This should include a review by young people which could be undertaken as a group or through outreach in clinics. A re-build could be considered to include interactive aspects such as videos and blogs.

Recommendation 8: dsdfamilies website should include a 'current science' section which offers 'information and advocacy' around the scientific progress and current debates around differences of sex development. It is recommended that dsdfamilies look to other health conditions that have developed similar web-based information and see how these models were developed and what can be learnt from them.

Recommendation 9: The dsdfamilies website hosts a 'webinar' area and runs a regular

(monthly, every two months) webinar where experts in the field give presentations on topics suggested by stakeholders.

Collaborative working with healthcare

Recommendation 10: dsdfamilies works with the authors of Clinical Standards for Management of an Infant or Adolescent presenting with suspected differences of sex development (BSPED, 2017) to see how the charity can assist the implementation of the following aspects of this document:

1.IV Every family with a child/young person with a suspected DSD diagnosis should be encouraged to engage with an experienced DSD Psychologist /Psychiatrist/Mental health professional who is an integral part of the specialist DSD team.

4.II All families with a child/adolescent with a DSD diagnosis should be offered details of appropriate Peer Support Organisations

5.I All specialist DSD MDTs must have a mechanism to enable patient/ family to feedback their views and opinions to the DSD MDT.

6.I The DSD MDT must have an appropriate Transition pathway to adult care and ensure this is explored and discussed with each young person with a DSD diagnosis.

Recommendation 11: Those who produce the Standards of Care consider including a 'minimum contact' that families can expect of annual appointments, even when the child has no physical health requirements.

Recommendation 12: This consultation showed that children have varying degrees of understanding and some parents feel unable to have conversations with their child about their health condition. It is recommended that healthcare providers take a children's right approach and actively avoid stigmatising these health conditions and alleviate parental anxiety by having conversations with children about their health at all ages. Agreed protocol for this could be developed, where a child's health condition is spoken about to them in an honest and open manner from the point of diagnosis. This would need to be done in age appropriate ways, but would create an environment where talking and asking questions is encouraged and where the 'burden of explanation' is removed from parents.

Recommendation 13: dsdfamilies collates the current health guidelines for children with differences of sex development and includes these in the information hub. Where appropriate, dsdfamilies should work with guidelines authors and stakeholder group representatives to produce 'user-friendly' versions for young people and parents.

Recommendation 14: Community organisations and medical specialists work together to explore ways to educate non-specialist healthcare providers in differences of sex development and the experiences of families. This could include working with the Royal College of Midwives, Royal College of Paediatric and Child Health and those bodies that train student doctors and nurses.

Education and schools

Recommendation 15: In 2017 sex and relationship education became compulsory in UK schools. It is recommended that work be done to engage organisations such as the Sex Education Forum and the Equality Lead at the National Education Union, to explore how issues of differences of sex development could be raised to teachers nationally.

Recommendation 16: Organisations representing children with CAH liaise with the Royal College of Nursing and BSPED to highlight parents concerns on injections in schools and to find a way to work together to address this.

Public Awareness

Recommendation 17: dsdfamilies reach out to the FPA and Brook, two organisations that make excellent materials on puberty and sex education, to explore whether specific resources could be produced that reflect the needs of children and young people with differences of sex development, as well as including their experiences in generic materials.

Recommendation 18: As there are overarching themes of lack of public and public-body understanding, it is recommended that policy makers are engaged in a dialogue about the issues children and families face, and creating opportunities where children and parents can feed into policy and practice development.

Recommendation 19: dsdfamilies should consider ways to actively engaging the media and educate the public. This could be through a planned public relations project which creates confidential platforms for young people and parents to be able to speak on. Public Relations companies often offer charities pro-bono support in planning such activities, and this avenue would be worth exploring.

Including all communities

Recommendation 20: Finally, we are aware of the lack of Black, Asian and Minority Ethnic voices in this consultation. It is recommended that targeted work is developed here. This could start with a meeting of those providing healthcare in key geographical areas to share work that has already being done to reach these families. It is recommended that other health conditions are engaged to learn how they have engaged different communities and materials are translated into multiple languages.

Acknowledgements

We would like to acknowledge the following people and groups who spoke to us and engaged in this process, offering their experiences and views. We apologise if anyone is missing.

First and foremost, thank you to all the young people, adults and families who came to our events and completed the online questionnaires. Without this, there would be no report and we thank them for their time and honesty and for sharing with us some very personal experiences.

Thank you to: dsdfamilies Trustees: Ellie Magritte, Dr Julie Alderson, Sue Elford, Kate Davies, Professor Ieuan Hughes. The consultation team: Magda Conway, Dr Nina Callens, Jill Hellings, Susanne Lambert, Maia Thornton and Esme Smith. Barbara Savill. CAH Support Group.

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Thank you from dsdfamilies founder, Ellie Magritte:

This report concludes the specific dsdfamilies consultations project funded by BBC Children in Need and The National Lottery Community Fund. In some ways it also concludes an organisational transformation.

'You have a voice, and you will be heard.'

I would like to thank the following for the learning, friendship and support over the last years:

Families and leadership of the Spanish AIS-DSD group, grApSIA, especially Patricia; Families and leadership of the Italian AIS-DSD group AISIA, especially Paola; Leadership of the Dutch DSDNederland, especially Joke and Puck; Families of the American AIS-DSD group, especially Meg, Amber, Arlene and the many other old friends; Leadership of the American Hypospadias and Epispadias Association, especially Jim and Tiger; Daniela Truffer and Markus, Stop.IGM.

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For more information about dsdfamilies or differences of sex development visit:

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