

What we WISH our **parents** KNEW

Inter/Act is a national project led by young people with DSD/intersex traits, ages 14-25.

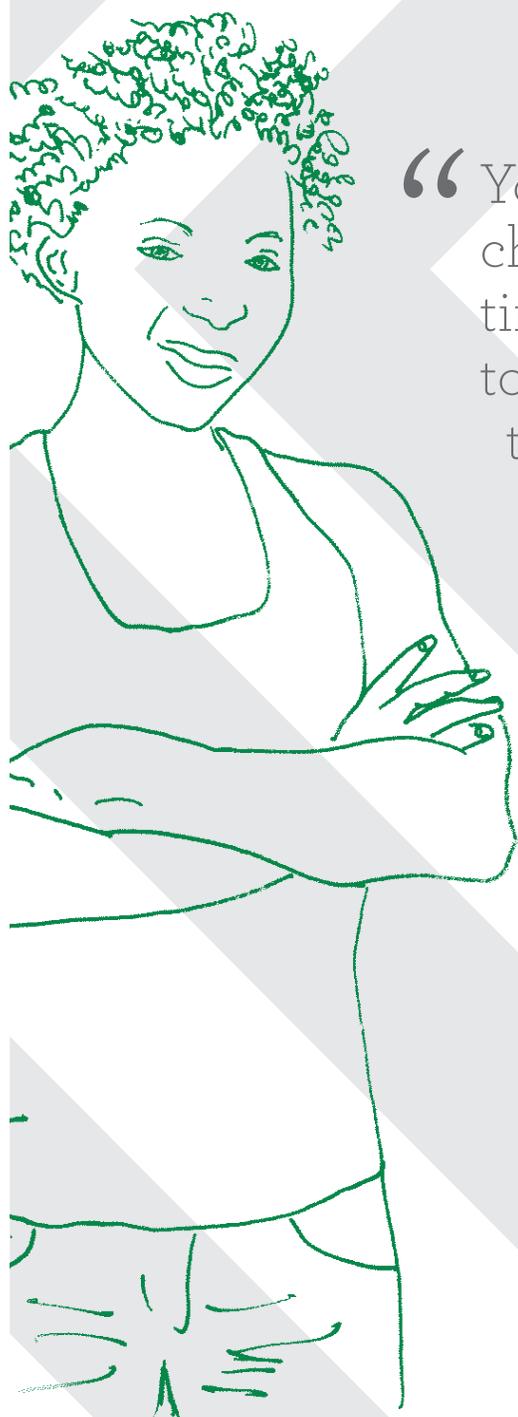
Telling our own stories and speaking our truths is vital; we decided that it was time to share our thoughts on what we wish our parents knew. Please help share this knowledge with anyone who may need it.

pass it on.



Understanding

- * Take initiative to meet other parents. Create a network for yourselves so you don't feel alone.
- * Don't make assumptions about how I'm feeling about things: ask.
- * Listen.
- * Be sensitive with your actions and words because I am the affected one, not you.
- * Yes, there are things that will affect you, but your priority is to be there for me as I go through a life-changing event.



“Your *feelings* about your child are **VALID**, but at the same time your intersex child will **GROW UP** to be an **AUTONOMOUS** person. You have to realize that your vision may not always be ***congruent with that reality.***”

Working Together

- * This is going to be a harder journey than you might realize.
- * Take time to cope with your feelings without me there.
- * This is not your fault.
- * Recognize how significant this is for me in terms of my identity.
- * Even though I have come to terms with my condition, that doesn't mean I've gotten over it.
- * Please don't tell me how I should feel.
- * Don't compare me to people who are “worse-off.”
- * This isn't something that you or I can go through alone; we need each other.
- * I need you to create opportunities to discuss my condition, I'm just a kid and might have a hard time doing that on my own.
- * Don't keep secrets from me. I don't want to wait until I'm older to find out you knew about this.
- * Give me information in chunks. Hearing everything at once can be overwhelming.
- * Communicate as parents before talking to me; you need to be prepared to handle my reaction together.
- * Be ready to answer my questions. The internet can be an intense place, and I don't want to search for answers there.
- * Biology textbooks don't have information on this.
- * Don't treat my diagnosis as a burden, and don't pity me. It makes me feel like there's something wrong with me.

“I might act like I’m okay, even if I’m not.”

Dealing With Doctors

- * I want both of my parents to come with me to appointments. It shows you care, even if you don’t end up staying in the room.
- * Sometimes I need to speak privately with a doctor. Look for those moments and ask me if you should leave.
- * Let me know what my rights are as a patient. If you don’t know, then find out before putting me in an unsafe environment.
- * Doctors are going to be very curious about my body. Don’t let them treat me like a guinea pig.
- * I may not understand how having a roomful of doctors examine me might affect me later. Help empower me to say ‘No’ more often to teaching opportunities and multiple doctor exams.
- * Do your own research, become an expert in my condition. Don’t let any doctor talk you into something irreversible without being fully informed.
- * Gyno exams are bad enough as an adult. Can you imagine how they must feel as a child? Help me feel as comfortable as possible about these situations.
- * Include me in the conversation with my doctor. Don’t talk about me as if I am not there.
- * Be more informed about my HRT choices and offer insight about the effects it can have on my body. Be open to trying different options.
- * Don’t let doctors pressure me into immediate action. Often times it’s not necessary.
- * Consult a diverse team of professionals and community members who can help us deal with these issues.

Siblings

- * It’s important to keep the whole family in the know.
- * I may feel jealous of my siblings’ experiences during puberty and their ability to have children.
- * Tell me I am special and can be a parent without giving birth to a child.
- * I don’t think I’ve ever felt jealousy over the fact that my little sister and I have different bodies, just regretful that I couldn’t share my experience/wisdom with her when she went through puberty.

Therapy

- * Make sure I know that seeking help is an option.
- * Know that it is okay for me to go see a therapist and I’m not “crazy.” Having a DSD is hard to handle.
- * You are not failing as a parent if I ask to see a therapist.
- * Research support groups and ask if I would like to go to one. It is empowering to meet other people like me.
- * When I was diagnosed and found out that I was in the “middle”—it made sense. I went to therapy and considered all the logistics of transitioning based on how it would affect my family, friends and schools but never factored my own feelings into that equation.

Disclosing to Others

- * I wish I wasn’t left out of the conversation when you disclosed to others in the family.
- * Let me know if you want to tell someone. I know you need to talk about it too, but it’s my story and I need to know who knows.
- * If you’ve already told other people, please tell me. I might be hurt, but at least I won’t find out later on my own.
- * Help me think early on about the pros and cons of disclosing. Otherwise I may tell someone and regret it later.
- * Empower me to decide who should be told and who shouldn’t.
- * Be my advocate, especially if I’m too young to advocate for myself.
- * Ask me if it’s okay to send pamphlets anonymously to my school. If they know they have an intersex student, they may be more sensitive.
- * There’s a difference between privacy and secrecy. Telling me I can’t tell anyone makes it a very shameful thing.
- * Be sensitive when talking about “typical experiences.” Discussing periods or pregnancy when I’m around can feel hurtful.
- * Help family members understand the realities of my body, and that asking about things like my period can be triggering.

As guardians, your decisions AFFECT OUR DESTINIES. **REMEMBER,** each child is **unique** and we may have **different ways of coping.** Be *prepared* to give us **multiple forms** of support during our journeys.

Inter/Act is a place for young people with intersex traits or DSD to come together, express ourselves, and unite our individual stories to develop a voice for a new generation. We don’t always agree with each other, and we don’t expect you will either. Inter/Act is a project of Advocates for Informed Choice (AIC), www.aiclegal.org, and is funded through a grant from the Liberty Hill Foundation. Inter/Act-inter-actyouth.tumblr.com