

Closed Caption/Subtitles for Inclusion Video

0:00

[Music]

0:13

welcome to another edition of special needs jungle in conversation with today i have the privilege of talking to

0:19

two remarkable young disability campaigners george fielding and siena castellan they have graciously agreed to

0:26

answer some of your questions about what it's like growing up with a disability and what we as parents need to consider

0:32

as a as our children growing to adults firstly welcome to both and thank you so

0:37

much for agreeing to tackle a subject there seems to be so little information about it's almost as though society doesn't

0:43

want to recognize that disabled young people actually go through puberty too and have the same wants needs

0:49

rebelliousness and questions that their peers do so we really really appreciate the fact that you guys are willing to

0:55

sit and talk to us about this so to start off could you both please explain

1:01

a little bit about yourself your disabilities and how they affect you

1:07

sure so i'm sienna castleon i'm a neurodiversity advocate and author i

1:13

wrote the spectrum girl survival guide how to grow up awesome and autistic um i am autistic dyslexic dyspraxia and

1:20

i also have adhd it took me a while to get diagnosed with all of those differences but i'm

1:26

incredibly proud to have them and i really embrace all the positives that come with it and all the superpowers i

1:33

call them especially with my autism that has given me my love for math and

1:38

physics hi everybody my name is george fielding i was born with several cerebral palsy i

1:46

have been a manual wheelchair user since the age of uh four or five um and um i

1:53

have in my career been been a mentor to around about 500

2:00

wheelchair users across the country in my in in my role as the chair of the board of young trustees for whiz kids

2:06

and and since then since then have um grown to set up two

2:11

social care organizations the latter of which i i

2:17

i'm involved with now amethyst is a specialist in transitional care for young

2:22
disabled individuals and i have always been incredibly proud

2:29
of the identity that disability gives you

2:35
by our very nature i think like humans should be but every every

2:42
person with a disability i've ever met has different passions and different skills and

2:47
um having the ability to now for a living

2:53
demonstrate my passion for for supporting young people to have the confidence and

2:59
the ability to to access the society as they wish and and see them flourish with

3:06
me in the background and my team is such a joy

3:11
and what do you think of the key ways your disabilities have shaped your experiences as you've grown up both the

3:17
positives and the negatives yeah so for me

3:23
um my as i said my autism helped me with

3:28
my love for math and physics but there were challenges in that i was frequently bullied at school

3:34
um i had to go to 11 schools most of the changing was because of bullying um

3:40
teachers weren't accepting students was accepting everywhere i went i felt different and ostracized and it took me

3:48
a while to see that difference as a strength and the unique thing that makes me me

3:53
um and with all my learning differences my dyslexia my dyspraxia and my

3:58
adhd that made my school experience challenging at times

4:04
but when it came to doing my own advocacy work i found that all of those differences

4:10
were strengths you know my adhd and my dyslexia gave me all this creativity

4:16
that helped me when it came to setting up my campaign neurodiversity celebration week and my autism helped me with that

4:23
logical approach the time keeping and getting everything on track

4:30
and george for me i

4:35
have always been blessed i think with the maturity um

4:41
i have always been able to liaise and communicate

4:49
with adults and change makers because actually i learned

4:54

that if i didn't speak for myself and and assist others to speak to themselves
5:00
then arguably no one was listening um so that's the negative
5:07
i think that my entrepreneurialism and my love for
5:12
creating and listening to people with disabilities comes from
5:19
i distrust and it and i distrust and
5:25
and i having realized that distrust
5:31
now understands that i have the pressure and a privilege of being hopefully the individual that
5:39
people with disabilities and their families trust um you know but
5:47
but that maturity has also come at a cost um
5:53
the i
5:58
i don't feel as if i've ever met a young person
6:04
that is like me um and that and and and that and that is a
6:11
difference um it is a difference that people see and and here on a day-to-day basis
6:18
but as but as you grow older and are given more opportunities
6:24
to articulate your vision and and stamp your foot on society and those you work with
6:31
it does become a strength that's really interesting so actually it's it's um
6:36
it's kind of a gift and a curse i guess then and do you think that it's actually
6:42
society uh and the way they deal with you then that makes sort of some of the negatives as opposed
6:48
to actually there being a negative with the disability itself but
6:54
i think that people with disabilities have to
7:01
oh i certainly did learn to spot
7:06
those that wanted to change the system the innovators the the the communicators
7:12
the change makers the disruptors um because
7:18
indeed they are the people that i had to liaise with and my peers have to liaise with in
7:24
order just to live the life that we want absolutely for you um have you found that the most
7:30
disabling thing is sort of people's attitudes around you then
7:36
yes the most disabling thing is societal perceptions um and that's something that has really
7:42

been highlighted in lockdown so i've been staying home and i've been able to create my own environment and so

7:50

the lighting there's no fluorescent lighting there's only lighting that helps with my sensory processing difficulties

7:56

there are no loud sounds or um anything that gives me the anxiety

8:02

that i would get when i go into unfamiliar environments out in the real world and i haven't had any sensory

8:09

panic attacks in the last year for reference i would have them almost daily when i was

8:15

um you know living living life you know going to to work in person

8:21

using public transport multiple times a day and it really helped me to realize that

8:27

a lot of the challenges i had came from living in a world that wasn't designed for me um living in a world where when someone

8:34

did the blueprint for building they didn't think okay how would an autistic person feel with all these glass doors

8:41

and all these reflective surfaces um and that was what was giving me my anxiety and my challenges but when i've

8:48

been on my own i've been able to control my environment and give myself the adjustments that i need to be successful

8:54

i've had no problems um it's all just been the positives of my neurodiversities so actually it's

9:01

helped me learn a little bit more about yourself and so the environment that you work best in

9:07

yeah it's been a very empowering experience because when you're out

9:12

um you know especially talking to neurotypicals you know they just see all my differences as disabilities um there's

9:20

problems and i've always felt like their superpowers and it's been great to have that reiterated

9:26

this kind of experiment that the last year has been with kobe okay let's move on to the sticky subject

9:33

of puberty no pun intended there um so we all know that growing up and going to

9:38

puberty is pretty horrendous for most young people isn't it um but you know there is a fair

9:44

amount of support out there for young teens certainly at school um you know looking at sex education and pshg

9:51

um you know looking at body positivity and healthy living and things like that but do you think there's enough to help

9:58

disabled teenagers prepare for this period of their lives and if not what do you think could be improved

10:05

yeah i mean i think that especially for autistic girls there's not really

10:11

enough specialist support i'm i mean i feel like unless throughout the education system in general

10:19

autistic people neurodiverse people aren't included if they are it's an afterthought it's just kind of like set

10:26

up programs for neurotypicals and that means that you find that

10:32

in pshe you discuss dating but you don't discuss it in the detail that may be an

10:37

autistic girl needs and so they end up being taken advantage of by neurotypical boys who

10:44

see the relationship is in-game when the autistic girl you know doesn't have the social communication skills it's maybe

10:51

the person that she thinks she's dating and so she doesn't realize that this is just another form of bullying

10:57

um and those kind of discussions don't occur in the school environment

11:02

and it's up to the parents to support their children through that and then a lot of resources on it and so

11:09

you frequently find that a lot of people a lot of neurodiverse people have challenges in

11:15

that time in their life and that was kind of what drove me to um write my book the spectrum girl

11:20

survival guide and include a chapter on dating so do you think it's something that

11:26

schools actually need to pick up on and um perhaps deliver

11:31

more sort of autistic friendly pshe lessons to everyone or do you think it's

11:37

something that needs to be targeted towards um young people on the spectrum

11:42

specifically i generally believe that when it comes

11:47

to neurodiversity um making a lesson neurodiversity

11:53

friendly um actually helps neurotypicals as well because there might be a neurotypical in

11:59

that class who um maybe also doesn't have good social communication but they're not autistic

12:05

and they could really benefit from having that social communication really thoroughly dissected and explained to

12:11

them um and that goes with a lot of things like you know with my dyslexia i like

12:16

things written clearly on the board not in this squiggly handwriting that makes

12:21

it difficult to copy down that was something that i found challengingly dyslexic but there were other people in the class who didn't have that

12:27

difference who also just found it challenging and so i find that

12:33

making work accessible making classes accessible to narrative our students benefits everybody

12:39

now i completely agree with you and i think that you're absolutely right that actually making any kind of education
12:45
more inclusive helps everyone you know universally and
12:51
yeah george what was your experience well i i i would
12:59
again wholly endorse everything that cnn said i
13:04
i i believe that there is
13:12
a angelic purity that that society assumes that people
13:19
with his hand you know um and
13:24
and that and that doesn't
13:29
that that doesn't help in kind of kick-starting the conversation
13:35
around sex relationships and and and puberty
13:42
desexualize disabled people isn't it
13:58
you know and if it is tolerated you know or discussed
14:05
the assumption is that your partner your your sexual partner will
14:11
also have a disability um
14:16
or be a carer indeed and and
14:23
that that that that is very much
14:30
i think still still the case sadly
14:36
uh and and i would also say you know on the back of that
14:42
whether it's an environmental barrier or an attitudinal one
14:49
to to people with disabilities having relationships
14:55
there there there is a lot of harm
15:02
that is caused by the suppression of of human desires and human feelings
15:12
you have how did you learn about kind of like you know what sex would look like for you or
15:18
you know what some of the challenges might be what some things you would need to think about i mean did
you have any
15:25
kind of resources or help or anyone to talk to um what
15:30
well they there are there are two there are three
15:36

organizations i think speak on this particularly particularly well um

15:42

all of all all of which i i i admire and and and

15:48

were the source of my education but for you but but

15:54

but it was it was to to find them on the internet was a you know there weren't resources given

16:00

to me so that was kind of disabling hits horizons that is the online magazine

16:05

founded by martin sibley that's always had a intact fantastic section

16:11

on on sex and relationships there is the

16:16

um there is the actually the designers and the sellers of sex

16:24

toys hot octopus are are are an organization and actually

16:31

i think they became inclusive um by default in in in in the sense of

16:38

their first product um the feedback their first product was

16:44

was was was run was from a man with a kind of spine injury um

16:50

and and so they designed their product without really realizing that that that it kind of hurt

16:57

that it helped people with disabilities and and the last one is

17:02

an organizational campaign called supported loving um which is a much more

17:07

um kind of social care specific organization but but they are

17:15

the only organization i've really heard of or work with the offer specialist

17:21

uh training for people with learning disabilities um

17:27

on on sex and relationships um but the likelihood is the vast majority

17:34

of people listening to this and the vast majority of people out you know out on the world will never have

17:40

heard of those organizations um and

17:45

and it you know i'm i'm 26 now and and i and i

17:50

really do think that it took me until very recently

17:56

to publicly and proudly endorse what what i'd learned and seen from those organizations

18:02

um i i also do think that

18:09

in living our lives as we wish

18:16

there isn't much privacy anyway um

18:21

that or or there isn't or or there isn't much privacy to to support work that is done incorrectly

18:29

there that you know that um so

18:35

so the the the fine line i think

18:41

for me was actually realizing that

18:49

you know i didn't have to keep my relationships private and also with with um

18:58

teenagers privacy is a huge big deal as you go through puberty all of a sudden your own private space is really really

19:04

important and for parents of disabled children especially those who need help with

19:10

their personal care this can be a real struggle to get the right balance um so what would you say the ground

19:17

rules that parents should respect if their child needs help with their personal care in their teenage years

19:23

what what sort of message or you know tips can you give parents to

19:29

be able to respect that privacy when they're obviously also going to be

19:34

sort of dealing with their personal and intimate care at the same time

19:39

yeah i mean i would say definitely having a conversation

19:45

with i mean especially within the sphere of autism

19:51

sensory processing challenges that can arise um hygiene can be very difficult i

19:56

mean it just takes walking into super drug and looking at the shampoo bottles to see how everything's

20:03

you know fruity blast um pomegranate cocktail or like all these really strong

20:09

smells for the shampoo strong smells for the conditioner and then if you want

20:14

like a body wash everything some kind of strong mint or fruit and that was something i really

20:22

struggled with um just the sensory element of it because i'm very sensitive to smells

20:29

and so it took really having conversations and this happens you know with a lot of autistic individuals

20:36

where you have to find products that work for you and until you find that those products

20:41

it can sometimes appear that you might have a hygiene issue if you're struggling to wash your hair and having

20:47

parents who don't stigmatize that and instead try to problem solve like um my mother

20:54

for instance um i had a very difficult time brushing my hair because growing up i had very

20:59

long hair that would get very knotted and it would really hurt to have to untangle all of that and so she helped

21:07

me by you know we had a conversation about it and from then on i just kept my hair
21:12
short so that i didn't have to worry about um that kind of challenge and just the
21:17
problem solving element i think is something that a lot of parents should adopt instead of the stigmatizing
one
21:25
where oh why do you have such knotted hair your hair looks like a bird's nest
21:30
not focusing on that focusing on a solution
21:36
and george i i would simply not not simply say i i
21:45
in the in in the in the personal care that i've had delivered to me
21:52
it's either it's always been on a direct payment
21:58
um which means that i or my mother in the earliest cases is
22:05
the employer um and the decision maker
22:18
you can't that you know
22:24
that it is it is the most intimate kind of
22:29
of customer service personal care
22:35
um and
22:40
i've i i think that that is the beauty and the joy of it is that when
22:46
there is a comfortable relationship like that it it
22:51
it it is you know it is one built
22:58
on trust and it is and it is one that can truly transform an individual's
23:04
uh self-confidence i
23:11
think i've always realized that
23:17
not to be depressing or morbid but my parents won't be around forever
23:22
um the the and
23:30
so so that this that there has always been a
23:36
kind of what's my backup plan um
23:42
what no who and
23:47
i it has always been
23:54
incredibly important to me that the relationship i have with my family is one built on friendship

24:00
rather than contractual due to your service

24:06
um i think though

24:14
that that it is very easy for parents to slip into

24:21
the assumption and the belief that is healthy and right

24:26
for them to carry on give you know that

24:31
there is there is an inherent pressure i think in the delivery of personal care

24:38
uh to a young person that it is it is probably true that

24:44
no care provider will know that young person better than their parents but does that but that that doesn't mean

24:51
that parents are the best providers on a day-to-day basis

24:59
and also i guess by um working with carers you also learn more about yourself and how to ask

25:07
for help which i think can be you know quite a difficult thing for children to learn if you've always got a parent sort of

25:15
there caring for you it doesn't kind of give you the space to actually learn in

25:20
what you can do by yourself and actually how to ask help well well

25:26
well well this is the reason that a lot of a lot of providers

25:32
are not good at transitional care services

25:39
you can't really go from any kind of residential campus environment whether

25:45
it be a college or a school or or a home into your own flat overnight

25:52
it it doesn't work

25:57
we i think we need to be honest with ourselves that people with disabilities

26:04
they they develop different rates different times

26:11
but but but also um the assumption

26:18
that at 16 at 18 at 25 they've learned all the skills that they

26:25
need to be independent

26:30
it's a misguided one because like please turn 18 and that's it you've got it

26:35
you know so so so so in terms of the work that i do

26:41
i still proudly call myself an educationalist

26:46

right because because there is because there is some because actually

26:53

true transitions and true developments into independent living are phased and

26:59

they happen at the right time and and

27:05

skill is in knowing when

27:11

and knowing how to feed in and phase

27:17

that skills development into the transition into independent living i do also think from a parent's point of

27:24

view it's about remembering that privacy is a right and even if you are

27:32

looking after your child's very personal and intimate care they still have a right to privacy so it's like setting

27:40

ground rules like always knocking before you go in you'd always knock before you go into any other teenager's room and

27:47

you know just because you're you know perhaps doing very intimate care with your child doesn't mean they don't deserve that same

27:54

privacy it's a right as far as i see and certainly around puberty because we

27:59

all know how self-conscious young people can be about their changing bodies

28:04

and i guess that leads me on to the next question which when you have a disability and you

28:11

perhaps were different to your peers that can be quite overwhelming in an age where you just want to fit in

28:17

um so how do you think parents can encourage their child to love who they are

28:23

if they're starting to dis to view their disability in a negative light

28:28

yeah i mean i think that it's really important to empower your child i mean for me when i

28:34

went through the school system all i ever heard were the negatives of my differences

28:40

um when it came to dyslexia i just got constant grief for my spelling

28:45

you know with my dyspraxia um sport teachers hated me um i was always coming

28:52

home crying after every sport lesson because my sport teachers would say horrible things to me

28:58

um adhd i mean teachers would call me you know a space cadet they'd say oh you're just

29:05

not paying any attention when i was really trying um and so i would always

29:11

come home with the negative ideas of my neurodiversity and with autism that was amplified

29:17

because i was bullied for my autism um and my mother did a really good job

29:23

of just trying to keep me on track and trying to keep me focusing on the positives and it took me a while to

29:28

really embrace that message and it really it took my neurodiversity work as well

29:34

and all the research i did and i started finding all these positives that nobody's told me when i was getting

29:41

diagnosed people didn't tell me when i was in school people didn't tell me things like um with adhd there are more theta waves in

29:49

the brain and theta waves help with deep relaxation and so in fields like surgeons

29:56

firefighters police officers it was surprising but astronauts they're a

30:01

really high percentage of astronauts with adhd and it's all because those are areas where you need to keep calm under

30:07

pressure and individuals with adhd have that advantage because of these fetal waves in their brain and that was something

30:14

that when i found out i thought that makes complete sense because of all the

30:19

neurodiversity work that i do it can be stressful to get up on stage and to give these speeches

30:25

and i was able to manage it in part because of that side of my adhd

30:30

and there just isn't enough information out there to give people the positives and so i think that as a parent it can

30:36

be incredibly helpful to research all of that and to

30:42

focus on differences and not so much focus on the

30:47

disability aspect and george how did how what what do you think

30:54

i was very lucky that both my parents worked full time

31:02

i'm not saying there's not there's anything wrong with you know with those that don't but when

31:07

i reflect on it that was the route i think to

31:14

to my self-discovery

31:20

that actually my parents didn't have the time

31:26

to to advise or keep an eye on me

31:34

actually what they

31:40

what they soon realized was and it is still true to these days that

31:46

i'm a very compulsive um instinctual person um

31:52

and they

31:57

my parents have always respected when i've made my mind up

32:06
and and
32:13
and that and they have never questioned that um
32:21
my parents have always understood as well
32:26
that i am my best
32:33
when busy and we're not thinking we're not overthinking um
32:38
uh i didn't go and see my university apartment
32:45
before i moved in i didn't discuss it with my parents before i move in i
32:51
just moved in uh
32:58
um whilst knowing that they were always there kind of 45 minutes away and and
33:05
and would pick up the phone when when when and when and if i called but
33:12
but but but there were that but there was a certain sense in which
33:20
i as an individual
33:26
i have always
33:32
been been able to be my own sounding board if you in the same vein always viewed
33:40
your disability positively or have there been times and certainly when you're going through puberty
33:46
um and perhaps more aware of others around you have you ever found yourself
33:52
actually viewing it negatively or has it always been kind of something you've completely felt comfortable with
33:59
my biggest realization renata i think
34:04
was in some way we are all disabled because and there's a universalism
34:14
to disability what what what i meant by that is whenever
34:19
whenever i'm working or speaking to somebody
34:29
i am able to spot not in a negative light but in a
34:34
positive light what their weaknesses are and the things that join us together now now
34:41
now why do i say that in in in answer to your question
34:47
um
34:55
we if
35:00
if it is if it is environment in society that's the problem

35:07

then there are examples that you can use to articulate

35:14

what it means to be disabled

35:20

so that others can relate because because if you put my sister in a room

35:26

full of spiders i'm a much better person than she is you know because she has a phobia

35:35

now now but but really

35:42

that lens that way of seeing the world

35:47

help me understand my own humanity in relation to others

35:54

uh and actually the fact that

36:02

if i'm strong in believing that in some way everybody's disabled

36:08

then then in some way we all have our own weaknesses and our

36:14

and our own struggles our own desires our own emotions

36:21

it sounds very much to me like um your family set up gave you quite a lot

36:26

of room to kind of like be a team basically to to find your own way sienna

36:33

what about you do you feel like your parents got the fine line between support and money coddling rights for

36:40

you do you feel you have the freedom to make mistakes and you know learn about yourself and to

36:46

experiment with things and things like that yeah i definitely

36:52

made a lot of mistakes looking back um when i was younger and newly diagnosed

36:57

because i was diagnosed as autistic when i was 12 and so a lot of

37:03

kind of the beginning of my teenage years was spent figuring out how my autism

37:08

affects me and playing around with different adjustments and different ways of

37:13

adapting my routine to make life easier for me and my parents really helped me do that

37:21

um from my mother's perspective she always treated me like an adult and

37:27

that's something that um i really appreciate because i think that it helped me embrace the maturity that i

37:34

had um but it also meant that now that i'm 18 and i've moved out from

37:40

home it didn't feel like it was this big change like all of a sudden i was becoming an adult because my mother

37:47

always treated me that way um she let me make decisions for myself and it was

37:53

very much you guide this and i will support you along the way but you make those

37:58

decisions um you know she told me you know your autism best you know what works for you

38:05

and so when i was in the school system for instance i would tell her kind of what reasonable adjustments i needed and

38:12

why i needed those and then she would go into meetings and she would ask for that for me

38:17

but there wasn't this element of her deciding on my behalf what i needed

38:23

or talking for you yeah and i think that that was something that really helped me growing up and as

38:29

that leads me on to the next thing i want to talk about which is uh social media

38:36

and you know a lot of parents rely on social media to be able to talk to other parents and it's a very healthy way to

38:42

find tips ideas and to share experiences but there's actually been quite a backlash recently from the actually

38:48

autistic um like movement on twitter who say that parents of autistic

38:55

children shouldn't be allowed to talk about autism because they're not the ones living with it and so only autistic

39:01

people should be allowed to operate so what do you both think about um sort of

39:06

this rise in parents talking about their children's disabilities online and do you think it's helpful or harmful and

39:13

what things do you think that we need to take into account when we're talking about our children as they get older

39:21

yeah i think that there is a split so there's some communication that is incredibly

39:27

productive and helpful um i'm an autistic woman there's not a

39:32

lot of resources for autistic girls online and i found a lot of what helped me

39:38

through mom's net actually looking at what other parents were posting but what

39:43

i was looking at was incredibly productive um i remember one post i read i was i

39:49

struggled to brush my teeth that was something that always stressed me out and i had no idea why it stressed me out and somebody on mom's nerve said that

39:55

they got their child to switch to a toothpaste that didn't have mint in it and that they were now able to brush

40:02

their teeth because the problem along with this really strong taste of mint

40:08

and so i went and i got toothpaste that wasn't flavored and i've never had a problem since with brushing my teeth

40:14

that hasn't because i used to really resent doing that and that was advice that i found from

40:20

moms that that was advice that i kind of had to find there because there were no other resources and so i don't want to

40:26

bash people doing that what i do think is inappropriate is parents that over

40:31

share about their child's life you know if the idea of infantilizing autistic

40:38

adults is something that i think shouldn't be happening on social media you know if you have a

40:44

20 year old adult you would ask their permission before sharing their life story

40:50

and intimate details of their life online but they see it as because i'm maybe the

40:55

carer of this person i have permission to share all of this private information

41:01

and i think that that's something that has no place on an online platform and also

41:06

neurotypical parents making value judgments about autism

41:11

when you look at a lot of the autism speaks campaign information

41:16

it's a lot of neurotypicals making autism out like a disability that needs

41:21

to be cured um because they're just looking at it from this very limited point of view

41:28

with all of the misconceptions and stigmas that come from living in a society that is ableist

41:34

if you were to get a group of actually autistic individuals individuals like myself who are really

41:40

empowered by my autism we wouldn't all be campaigning for eugenics and for

41:46

autism to be cured and i think that that's something that i really struggle with that and that is hard for me to

41:52

understand at times that the loudest voices within the autism community

41:58

are people who are not autistic and that's something that needs to be corrected

42:04

and george what's your take on it i

42:12

[Music] i again completely agree with siena on on

42:18

the on on the idea

42:24

i i think that there are

42:29

certain things and certain boundaries and something she can't you you you shouldn't share

42:36

on on social media

42:41

i is especially especially in especially in a caribbean role

42:48

um i i worry

42:55

that whilst we talk about the fact that the

43:01
deep democratization of social media of of media the fact we've all got our own
43:06
platforms and you know as a campaigner that's fantastic
43:12
but but there's something societally wrong
43:19
in the fact that for a lot of people with disabilities and their families social media is the only
43:25
platform that they believe works you know
43:30
um all that they have you know um
43:37
i i i i therefore believe that the overuse
43:46
of social media where it is overused by
43:51
by apparent carers is actually
43:57
a demonstration
44:03
of of desperation quite a lot of the time of
44:08
of the fact that actually a lot of the ordinary channels
44:16
all the channels that we expect to work in favor
44:21
of people with disabilities often don't being a carer is
44:28
something that people ought to be very proud of um you know
44:36
um it's and
44:41
because it's because it's because it's very human and often a very selfless thing to do and and and
44:48
it's something that deserves a lot more rewards monetary and otherwise um and a lot more recognition
44:58
um but but being a carer being a parent carer
45:06
can't be the only thing you do i mean both of you you know you both
45:12
have achieved amazing things in your lives considering you know i know sienna you had a very difficult time
at school
45:19
um and now you're off to stanford university which is amazing i mean george you've got a british empire
medal
45:26
you're a prolific public speaker i've spoken with you at a couple of events you're a fundraiser and campaigner
cnn
45:33
you've won awards for your advocacy you're a published author founder of the neurodiversity celebration
week i mean
45:40
you both have achieved so much um do you think something like you

45:47

you've used your experiences as disabled young adults to achieve these great things and um

45:52

you know what would you say was the hardest part of dealing with a disability as you're growing up

45:59

and how what helped you turn things around to become these amazing advocates

46:04

that you are today yeah i mean i think that definitely something i struggled with when i was

46:11

younger was final expectations that were put on me

46:16

and the stigmas and misconceptions around disability um something that

46:22

really was a turning point for me um was adopting a more strength-based

46:28

model um at school there was this big focus on identifying your weaknesses and spending

46:35

all your time and energy trying to improve those areas and so i would go home and spend hours

46:41

practicing my spelling tests and practicing my my sport because teachers were

46:47

constantly telling me how often it was about because of my dyspraxia and

46:52

it was just a system that was obsessed with identifying flaws

46:58

and so every day when i would come home from school it was just weaknesses that i could see in myself

47:04

and i would try to change them but you're never going to no amount of time that you dedicate to

47:11

working on your spelling it's going to change the fact that you're dyslexic that's just the way that your brain is shaped

47:17

and i reached a point where i decided that i'm just going to give up on all those weaknesses i'm just going to let

47:22

them be weaknesses and instead dedicate all my energy towards finishing

47:28

my strengths and immediately my mental health improves because i was seeing progress in a way that i wasn't when i was

47:35

practicing my sport with a multi-coordination disorder um and that was what

47:40

got me i guess if you call it success or what i've achieved now i mean getting into stanford to study

47:48

mechanical engineering that was me spending my time and energy on math and physics the areas that i'm

47:54

passionate about the areas that i'm good at instead of spending my time in english because there's no way i would have been

48:00

accepted if i marketed myself as someone who was good at english or history because that's not my area

48:06

um and so adopting that strength based model and that was something that actually went through into my

48:12

advocacy as well just looking at

48:17

the skill set that i have and how i can best utilize that um and finding platforms that work for

48:23

me and finding you know areas that don't work so much areas that i struggle

48:29

with and then just deciding okay well i'm not going to do that side of the app i can see that

48:34

um and now looking at where i am at this point i still can't spell i'm

48:40

atrocious at sport but i don't care because i have um

48:45

all these talents that i use on my phone everyday basis and i really embrace and i'm proud of

48:51

that's a very very powerful takeaway and george

48:57

i'm i'm i'm still absorbing what was i think

49:03

very close to perfection in in terms of

49:08

in terms of seeing those answers there the greatest thing that i now have is

49:14

that i take ownership of my own brand and my own identity

49:21

i am very proud of everything that i have done and that i do

49:29

but but actually

49:34

there is i can speak very eloquently about how i

49:43

and they just have been very disenfranchised about through systems and structures um

49:52

my school didn't want me you know i i had the best thing about my school was it

49:58

was close to a train station so i could escape to london you know on a day-to-day basis and and and

50:05

you know and and um you know i

50:11

i have never really been able to claim the statutory support

50:18

that i could have done because i haven't wanted to waste my time picking up the phone and and speaking speaking about

50:25

myself for myself

50:30

the the the

50:35

what what but what but what i have realized

50:43

and and what i believe you know is quite powerful

50:50

is that

50:56

there is a fine balance to be made between working in the system

51:02

and and using your story

51:07

[Music] to change practice

51:13

i i believe that i

51:20

that actually that that actually

51:26

five ten years ago i was just happy being the campaigner

51:33

and the mentor and the fundraiser with the megaphone

51:39

more and more now i want to put the microphone down

51:44

and get my hands dirty and it takes a lot of confidence i think

51:52

to and this thing i'm proud of actually on a day-to-day basis be engaging in the

51:58

system to disenfranchise you that hurts you

52:05

um i i wouldn't have had that before

52:10

i wouldn't have had that before um so i have been able to transport transfer

52:18

that hurt and that disappointment

52:25

into a professional

52:30

job and demonstrate that actually those i care for

52:36

will not principally and value and through my own values they will not experience the

52:41

things that i have done but in order to do that i've had to have conversations

52:47

with people and of the nature that i may not have wanted to

52:53

five years ago but that's huge thank you both for you

52:58

know agreeing to talk to me about this and being so open and so honest um

53:04

we hope everyone's found it really interesting and informative um if there are any other areas you'd like

53:09

us to explore further you know we don't mind exploring the different topics or if you've got more questions for either

53:15

george or siena do let us know um you know because we can always do another video if i can persuade them to give up

53:21

some more of their time um but for now thank you so much guys we really really do appreciate it and we hope that people

53:28

have got some useful information out of it

53:34

[Music]