

RESPECTING

DIFFERENCE

NOVEMBER 2018

CHANGING FACES



Looking different in a world where beauty and physical appearance are valued so highly can be extremely tough. At Changing Faces we hear every day about the challenges that young people with a visible difference face in their daily lives, where even stepping out of the house can be hard.

IT'S NOT MICE WHEN YOU'RE WALKING DOWN
THE STREET AND YOU FEEL SHY TO SHOW YOUR
FACE... THAT'S A HORRIBLE. HORRIBLE FEELING
AND THAT'S WHAT I FEEL:
Theo*, age 11

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I USED TO COVER MY BIRTHMARK UP QUITE A LOT IF WE WERE GOING OUT, JUST BECAUSE I FELT I COULD HAVE FUN AND ENJOY MYSELF WITHOUT WORRYING ABOUT OTHER PEOPLE:"

Sophie, age 15

Speaking with independent researchers from CHILDWISE, eleven young people with disfigurements and their families opened up about what it is like living with a visible difference in the UK today. What are their thoughts and concerns? How do they cope with the daily grind of stares and comments on their appearance? How do their families respond?

Our research reveals not only how hard it can be when you 'look different' but also that young people with a visible difference show remarkable resilience and often develop their own ways of coping.

What's clear is that the words people use and the way they act towards young people who look different can have a real and significant impact.

Young people with a visible difference want to see a world where people respect and understand difference, including at school, in their homes and communities, and online.

KEY POINTS INCLUDE:

LIVING WITH A VISIBLE DIFFERENCE

- Young people living with a visible difference often face persistent scrutiny and negative reactions from other people
- Coping with negative reactions about appearance can have a real impact on young people's wellbeing – from feelings of insecurity and isolation to depression
- Yet living with a visible difference can spark a resilience and maturity from a young age

SUPPORT

- Family and friends are the biggest source of support for young people with a visible difference
- Yet young people who look different often miss the opportunity to connect with other young people who have similar experiences
- When support services are accessed, the results are very positive showing just how important they are for young people and parents

APPEARANCE-RELATED BULLYING

- Appearance-related bullying is commonplace and even when schools are aware of the problem, most are unable to stop the bullying
- The transition to secondary school can be a particularly difficult time
- Bullying is not confined to schools young people with a visible difference face unacceptable behaviour even just going to the shops or having a meal with family

POSITIVE ROLE MODELS

- Young people are acutely aware of how 'beauty' and visible difference are portrayed in the media
- From a young age they are exposed to negative stereotypes, for example characters with scars are almost always the 'baddie'
- Young people feel strongly that there is a greater need for more actors with visible differences to play positive characters

WHAT WE WANT TO SEE CHANGE

BULLYING AT SCHOOL -

to foster face equality in schools and tackle appearance-related bullying, there's a need for specific support and training targeted at teachers and schoolchildren

SUPPORT -

young people should have access to support early, including information and advice online, a safe space for peer to peer interaction, or professional 1:1 support

BULLYING ON SOCIAL MEDIA -

social media platforms should adopt a zero-tolerance approach to appearance-related trolling and abuse

POSITIVE ROLE MODELS -

the media and creative industries should increase the number of positive role models with a visible difference

ESSANDRAS STOPPS

Alessandra was born prematurely, with a cross bite and Necrotising Enterocolitis (NEC). This meant that, as a baby, she had to undergo surgery to remove part of her bowel, which has left her with a scar across her stomach.

In the past, Alessandra has received negative comments and stares from strangers for her cross bite and her scar. However, she has also had people ask more politely why she has a scar. Both experiences made her more aware of her appearance.

Her mum says that she noticed a difference in her behaviour when she was 11 or 12 and that Alessandra became quieter and would worry about everything, ending up in tears most nights.

By attending Changing Faces workshops, Alessandra met other people who have a visible difference:



JUST BEING IN A ROOM WITH PEOPLE AS OPEN TO TALK ABOUT IT AS YOU ARE. IT MAKES YOU FEEL YOU'RE NOT ALONE. YOU REALISE THERE ARE OTHER PEOPLE LIKE YOU."

Alessandra says that Instagram can be difficult for young people who struggle with their appearance, as it is a place where people only show the perfect side of life.



I'VE POSTED PICTURES MORE RECENTLY WITH MY SCAR EXPLAINING MY STORY RECAUSE I NO LONGER FELT LIKE I NEEDED TO HIDE IT. I THOUGHT IT WOULD BE RETTER FOR MY FRIENDS IF I POSTED IT AND SHOWED THEM THAT I'M NOT RLENDING IM. RECAUSE THAT'S NOT WHAT WE SHOULD DO:"

Last year, Alessandra considered corrective surgery for her cross bite but decided against it because she now feels her different appearance is part of what makes her who she is.

Alessandra wants people to know that,

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REHIND EVERY SCAR THERE IS A STORY. AND THE SCAR IS JUST THE FRONT COVER - NO ONE CAN REALLY JUDGE YOU UNTIL THEY READ THAT STORY."

SCARS AREN'T JUST
SCRIBBLES ON YOUR
BODY. IT'S THE ARTWORK
THAT YOU CALL YOUEVERYONE'S REAUTIFUL
BY BEING THEMSELVES:"

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SOME PEOPLE STARE AT ME IN A VERY RUDE WAY... AND IT'S LIKE I'M AN ALIEM... BUT WERE ALL HUMAN."

Callum, age 11

Callum's experience of living with a visible difference is, unfortunately, not an isolated case. In a world which values a narrow definition of beauty, it can be extremely difficult if you look or feel different. This is especially the case for the 86,000 children and young people in the UK today with a significant disfigurement.

Many of the young people we spoke to were very aware of the negative reactions of others. A prolonged stare, a finger pointed in their direction, a group of friends all nudging each other when they walked past – our young people often experience these on a daily basis. Quite often parents are unaware of quite how difficult things are:



HE DOESN'T NOTICE. IT'S NEVER AFFECTED HIM. HE IS NOT ONE OF THESE PEOPLE THAT HAS BEEN BULLIED OR ANYTHING LIKE THAT..."

Theo's Mum



I DO NOTICE IT. LIKE I WAS OUT
IN THE STREET TODAY AND THE
AMOUNT OF PEOPLE THAT STARED
AT ME WAS UNBELIEVABLE!

Theo, aged 11

Most of the young people we spoke to had insecurities and worries about their appearance – the daily reality of living with a visible difference is clearly hard to deal with at times. One boy said that he wanted "people to understand – if they were me, would they like to be stared at 24/7 and looked at weirdly?".

All of the young people felt strongly that they didn't want to be defined by their appearance – but not all were confident about embracing their difference. Some spoke about covering up with make-up or clothing. One boy said he deliberately wears clothes that cover the skin condition on his legs and arms.

Their experiences highlight just how tough it can be to feel different, especially during the teenage years when there is real pressure to 'fit in'. They talked of isolation, even when they had the support of their family and friends. Even the youngest confessed to feelings of depression when they thought about their appearance, reflecting our previous research that:

ONE IN TEN (10%)

say that they're depressed about the way they look

Two young people said that they had thought about 'not being here anymore'.

A few admitted that they sometimes change the way they behave around other people, which reflects our previous research that concerns about appearance can influence behaviour. For example,

young people say they don't go out in public or to school because of how they look.

But living with visible difference also seems to spark a resilience and maturity. All the young people said they don't want to be defined by their difference.

"SOMETIMES WHEN PEOPLE SAY
SOMETHING THAT'S MEAN. YOU GET
DOWN AROUT IT. RUT THEN YOU JUST
HAVE TO CARRY ON WITH YOUR DAY."



"I DON'T REALLY SEE WHY I
SHOULD CHANGE MYSELF FOR OTHER
PEOPLE - IF THEY STARE IT'S THEIR
PROBLEM NOT MINE. I FEEL REALLY
STRONGLY THAT PEOPLE SHOULD
ACCEPT WHO THEY ARE AND
WHAT THEY LOOK LIKE:"

Sophie, aged 15

Parents also commented on how proud they were of their children and the way they have coped with difficult behaviour, such as staring or rude comments. Sophie's mum said,

"SHE HAS GROWN IN CONFIDENCE.
HER ATTITUDE IS WHY SHOULD I LET
OTHER PEOPLE ROTHER ME? IT'S
THEIR PROBLEM NOT MINE'. I THINK
THAT'S BRILLIANT."

Few young people looked to change their behaviour as a result of their experiences. Quite the opposite – they were determined to embrace life. They didn't want to be treated or viewed differently to other people their age. Many regarded their difference as an integral part of their identity – one girl had turned down surgery to minimise her visible difference, whilst another admitted she had made a conscious decision to stop covering up.

"I USED TO COVER MY BIRTHMARK UP QUITE A LOT IF WE WERE GOING OUT.
JUST BECAUSE I FELT I COULD HAVE FUN AND ENJOY MYSELF WITHOUT WORRYING ABOUT OTHER PEOPLE. BUT NOW I DON'T REALLY COVER IT UP ANYMORE.
I JUST TRY AND FORGET ABOUT... I'VE DEFINITELY EMBRACED IT MORE. AND I'VE DEFINITELY LEARNT THAT JUST BECAUSE I HAVE A BIRTHMARK IT DOESN'T DEFINE WHO I AM:'

Sophie, aged 15

APPEARANCE-RELATED BULLYING

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HE DEVELOPED A TWITCH. HE WAS LOSING HIS HAIR IT WAS ALL DOWN TO ANXIETY. HE WAS BEING SICK IN THE MORNING:"

Mum of 11-year-old boy

Being out in public or at school can be difficult if you 'look different' because of the behaviour of

others. Our research found that over a quarter of young people have felt uncomfortable and walked away from someone with a visible difference, or know someone who has done this.

1 in 6

admit that they, or someone they know, have taken a photo of someone with a visible difference.

BULLYING AT SCHOOL

Appearance related bullying happens in schools across the UK, with almost half of young people with a visible difference affected. This type of bullying often gets worse as young people move to secondary school – with more than six in ten teens experiencing negative or nasty comments about their appearance.

Most of the young people we spoke with admitted they'd been bullied at school because of how they looked. They described physical abuse, rude comments whispered behind their backs or shouted out in classrooms, and behaviour that isolated them from others. They "pick one thing about you then that lasts the whole year," said one boy.

At its most extreme, one boy suffered prolonged physical aggression, simply because of the way

he looked.

"In my first school it was physical bullying. They pushed me on the floor. I think it was a bit because they were jealous of me because I was smarter than them and because of the way I looked."

Most young people said they tried to ignore the bullying, again reflecting their determination to get on with their lives and refuse to let it affect them. Others did tell their parents, often resulting in meetings with the school. The results are not always positive. The young person who experienced prolonged physical violence eventually did report it to a teacher. But the bullies were never disciplined and he ended up moving to another school.

Our research shows that the **vast majority** of those bullied for their appearance



said their primary school did not succeed in stopping the bullying.



The move from primary school to secondary school can be a particularly difficult time, for both young people and parents. Those who had already made the transition often highlighted it as one of the toughest periods. Sophie, who decided not to cover up her birthmark at secondary school, says: "One boy bullied me quite badly. He would shout things at me and call me 'iron burn' when he walked past. It went on for weeks and weeks."

Others told similar stories:

"IT WAS MORE WHEN I FIRST CAME INTO SECONDARY SCHOOL. FROM ABOUT YEAR 7 TO YEAR 8. YOU'D HAVE PEOPLE CONSTANTLY SHOUTING ABOUT IT AND MAKING ME FEEL REALLY UNCOMFORTABLE:"

Daisy, aged 14

For those yet to make the move, it was also a source of real anxiety. One of the girls described feeling nervous about what the other children would say: "I feel like, because I'm not the same as everybody else, and I look a bit different, they'll probably be like 'oh god, what's wrong with her'".

Leaving behind a familiar environment, and strong relationships with friends and teachers, to meet

new people and start all over again is often tough for young people with a visible difference.

"I'LL BE KIND OF SELF-CONSCIOUS ABOUT WHAT THEY'RE SAYING AND WHAT THEY'RE THINKING. AND WHAT THEY MIGHT BE SAYING TO MY OTHER FRIENDS BEHIND MY BACK."

said one girl.

Not only is it an unsettling time for young people, but for their parents too. One mum said she planned to speak to the new Headteacher to see what could be done to ensure pupils were more understanding and considerate towards



BULLYING IN PUBLIC

For people with a visible difference, a trip to the shops, a meal in a restaurant, even just walking down the street can involve a level of scrutiny that anyone would find hard to deal with. The majority of the young people we spoke to had encountered persistent and rude staring: several had been verbally abused or heard insensitive comments.



IT'S NOT NICE WHEN YOU'RE WALKING DOWN THE STREET AND YOU FEEL SHY TO SHOW YOUR FACE...
THAT'S A HORRIBLE. HORRIBLE FEELING AND THAT'S WHAT I FEEL!

Theo, aged 11

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When Ellie-Mae was born, her mum Jane still remembers the horrified look that the midwife gave her. Ellie-Mae had a bilateral cleft lip and palate and at six months she had the first of many operations.

Jane remembers the rude remarks whenever she took Ellie-Mae out -

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I WENT SHOPPING FOR BARY CLOTHES AND ANOTHER MOTHER IN THE SHOP TOLD ME THAT I SHOULDN'T BRING ELLIE-MAE OUT IN PUBLIC I WAS SO SHOCKED AND UPSET."

Jane says it was very hard and people would stare at Ellie-Mae when she went out because she looked different.



PEOPLE NEED TO BE MORE ACCEPTING OF DIFFERENCE. NO-ONE'S PERFECT AND JUST BECAUSE YOU DON'T LOOK LIKE OTHER PEOPLE DOESN'T MEAN YOU ARE ANY LESS CAPABLE. WHEN SHE WAS BORN I JUST LOOKED AT ELLIE-MAE WITH HER SPARKLING BLUE EYES AND THOUGHT HOW BEAUTIFUL SHE WAS:"

When Ellie-Mae was eight years old she was bullied by a couple of older girls at her school. Ellie-Mae says she remembers them telling her 'You're not nice, you're not normal' and feeling scared.



SHE WENT FROM BEING A HAPPY LITTLE GIRL WHO WAS DOING REALLY WELL AT SCHOOL TO A GIRL WHO WOULD CRY. WHO DIDN'T WANT TO GO TO SCHOOL AND WAS REALLY UNHAPPY".

says Jane. Although the school intervened, Jane had to prompt them to take action and the bullying went on for a couple of years. Jane contacted Changing Faces and both her and Ellie-Mae received counselling and support. Changing Faces also worked with the school. During this time Ellie-Mae grew in confidence, building a strong group of friends. This support continued as Ellie-Mae prepared for the move to secondary school.

While secondary school has been a challenge, especially as it has meant going from a school with 100 pupils to one with over 3,000, Jane is incredibly proud of how Ellie-Mae has coped:

SHE'S HAD A TOUGH JOURNEY BUT SHE'S NOW GOT A GOOD GROUP OF FRIENDS AND SHE'S PROUD TO TALK ABOUT WHO SHE IS. I THINK SHE'S A MUCH STRONGER PERSON BECAUSE OF EVERYTHING SHE'S BEEN THROUGH:" Ellie-Mae says,

10

I LIKE BEING ME AND I TRY
AND JUST BRUSH IT OFF
IF PEOPLE ARE MEAN OR
IF THEY STARE. IT USED TO
MAKE ME UPSET BUT NOW
I WANT TO CHANGE HOW
PEOPLE ARE AND MAKE THEM
UNDERSTAND WHY THEY
SHOULDN'T STARE OR LAUGH
BEHIND MY BACK"



Some try and ignore the stares and some parents admitted that they hadn't realised what was going on until much later. Sophie's mum says: "I was completely oblivious. We would often come back from a day out and I sort of could tell it hadn't been a great day and I'd say you know, 'did you not enjoy yourself?' and she went "well everyone was staring and pointing" and I felt awful - she hadn't said anything at the time."

The parents we spoke to were understandably protective. One mum confronts people when they stare at her son, and often tells them to 'mind their own business'. Another spoke about having to

shield her son from the stares
when they are on the tube.
Despite this he did notice:
"THEY WERE JUST
TOWERING OVER ME.
STARING AT ME AND
IT WAS HORRIBLE:"

"WE'RE STUCK IN A PLACE AND WE CAN'T GO ANYWHERE... WE DON'T WANT TO START AN ARGUMENT. WE WANT TO BE PEACEABLE. SO I JUST PUT MY BODY IN FRONT."

Mum of 11-year-old boy

Some young people mentioned they are more tolerant of children looking at them in public and find adults harder to deal with:

"IT IS MAINLY KIDS THAT STARE AND ORVIOUSLY NOW THAT I AM OLDER I KNOW KIDS ARE CURIOUS WHEN THEY SEE SOMEONE DIFFERENT OR SOMEONE THAT THEY ARE NOT USED TO. THEY ARE GOING TO LOOK AND THAT IS FINE BUT WHEN IT IS ADULTS THEN IT IS A BIT AWKWARD."

Hannah, aged 17

BULLYING ON SOCIAL MEDIA

But it's not just school or being out in public that can be a problem. Young people with visible differences also have to contend with the world of social media. Their experiences of bullying online – from nasty comments on young people's photos, to abusive private messages – reflect our research that one in four young people have received nasty online messages. One of the girls we spoke to said she had received bullying comments about her appearance from an anonymous account.

in 4 copie

have received nasty online messages.

I THINK THERE NEEDS TO BE RESTRICTIONS ON WHAT PEOPLE CAN SAY TO OTHER PEOPLE ONLINE. PEOPLE SAY THINGS THAT THEY MAYBE WOULDN'T SAY IN REAL LIFE TO THAT PERSON."

Daisy, aged 14

This reflects our findings that

4 in 1

young people feel social media companies should react immediately if there are negative comments about people who look different.

1 in 3

of children and young people also believe it should be a crime to make negative comments on social media about people who look different. Previous research shows that as people get older online bullying continues, with almost everyone with a disfigurement having seen a social media post or photo that mocked someone's appearance.

Yet some young people found online bullying easier to deal with. They felt they had more control, pointing out that their accounts were private, meaning they could decide who viewed their content and who they wanted to engage with.

"IT'S SO EASY TO NOW TO JUST BLOCK
PEOPLE. SO IF SOMEONE'S BULLYING YOU
DON'T RESPOND. THEY'RE NOT WORTH
YOUR TIME. SO JUST GET RID OF THEM.
ALL THEY ARE IS A PROBLEM THAT CAN
BE ERASED. ESPECIALLY IF THEY'RE ONLINE
AND YOU'VE NEVER SEEN THEM BEFORE!"

Michael, aged 14

SUPPORT

So how do children and young people with a visible difference stand up to bullying and the challenges they face?

Family and friends play the biggest role in supporting and encouraging young people with a visible difference. Young people stressed how important these relationships are, and how much happiness, as well as security they bring. Yet some described missing the opportunity to connect with other young people with visible differences – to find people who can identify with their situation, who have shared experiences and know what it feels like to look different. Most had never met anyone who has the same condition as them, which heightened feelings of loneliness and isolation.

Many said they would love to speak to, or read about, other people who looked like them. They liked the idea of a safe space where they could talk openly and honestly with other young people who've had similar experiences. It's clear peer-to-peer led support could be very valuable.



WHEN I WAS YOUNGER.
AROUT NINE OR TEN I
FOUND IT REALLY HARD
RECAUSE THERE WASN'T
ANYONE ELSE AROUND ME
WHO HAD LIKE ANYTHING
LIKE A GENETIC DISORDER
OR ANYTHING. SO I FELT I
WAS THE ODD ONE OUT."
Sarah, aged 17

While it can be a source of bullying, social media can also offer support networks and opportunities to interact with other people who look different. One mum described how Twitter had changed their lives for the better: "we now have this extended Twitter family. The community have embraced him, and they know who he is now." One girl said she wanted to set up her own online support group to help find people who have the same condition.

Few of the young people that we spoke to had actively sought external support. In particular, many were reluctant to seek professional support, playing down any issues, with one expressing concern that they didn't want to 'make a fuss'.

Yet those who had already reached out to get support were all extremely positive.

The same was true for parents as well.

"YOU KNOW THERE WAS A TIME WHERE I COULDN'T SPEAK WITHOUT CRYING... I REALLY DO WISH THAT YEARS AGO WHEN [HE] WAS BORN THAT I HAD HAD THIS SUPPORT. I WAS VERY ALONE. VERY ISOLATED."

said one mother.

Clearly, there's a real need for support services for parents of children with a visible difference. Parents spoke about not feeling adequately equipped to support their child, especially when they encountered new experiences such as moving to secondary school, or a new diagnosis. One mum said if she had known about support services earlier, she would have "felt a lot better."

POSITIVE ROLE MODELS

The young people we spoke to were very aware of the lack of positive role models who 'look different' in the media, in films and on TV. Many felt this just reinforced the stereotypical image of 'beauty' and the need to conform.

"PEOPLE JUST LOOK FOR THE MOST HANDSOME OR PRETTIEST PERSON TO GO ON THE FRONT PAGE OF EVERYTHING. I DON'T THINK THAT'S RIGHT BECAUSE EVERYONE SHOULD GET A CHANCE:"

Theo, aged 11

For a young person to grow up watching films like the Lion King, Star Wars and Marvel's Wonder Women is to grow up being taught that having a scar or a disfigurement makes you scary, or not to be trusted. This can have a huge impact on young people living with a visible difference.

"I KNOW IN A LOT OF HORROR FILMS
THE PERSON WHO'S THE RADDIE HAS
MAYRE A SCAR ON THEIR FACE OR THEY
LOOK DIFFERENT I THINK IT'S GIVING
THE IMPRESSION THAT IF SOMEONE
HAS A SCAR THAT THEY'RE RAD:"

Daisy, aged 14

"YOU SEE ALL THE CELEBRITIES
WHO POSE AND THEY HAVE PLASTIC
SURGERY TO MAKE THEM LOOK BETTER
AND MOST GIRLS OR BOYS LOOK UP TO
THEM. YOU DON'T REALLY SEE PEOPLE
WITH A DIFFERENCE:"

Sophie, aged 15

4 in 10

children and young people

feel there needs to be more actors with visible differences playing positive characters in films or on TV.

So clearly, there is some work to be done with producers, film-makers and other industry professionals so that actors with visible differences are cast for their talent and suitability for a role, not simply based on their appearance.

It's clear from our research findings that daily life can be challenging for young people living with a visible difference. They are affected by the bullying and abuse they experience because of their appearance. Yet, many young people show great resilience and develop their own ways of coping with stares and negative comments. While this is admirable, our research clearly highlights areas where change and support is needed.

BULLYING AT SCHOOL

Teachers and school children should receive specific support and training to build their knowledge, skills and confidence to tackle appearance-related bullying and foster face equality in schools.

BULLYING ON SOCIAL MEDIA

Social media platforms must ensure that their community guidelines and terms and conditions support a zero-tolerance approach in tackling appearance-related trolling and abuse that targets young people with a disfigurement. They should organise training and support for staff that deal with user complaints.

SUPPORT

Young people should have access to support early, including information and advice online, a safe space for peer to peer interaction, or professional 1:1 support. Parents need to feel equipped to support their child with a visible difference, via support and advice online or facilitated access to other parents facing similar challenges.

POSITIVE ROLE MODELS

We're calling for a commitment from all those working in the media and cultural industries to increase the number of positive role models with a visible difference in the media. We'd like to see producers, film-makers and other industry professionals working with actors with visible differences based upon their talent and suitability, not simply their appearance. We would like actors with visible differences to appear in all genres of films with all character plots, where their differences are not the focus.

Changing Faces is the UK's leading charity for everyone who has a mark, scar or condition that makes them look different.

We want a world where everyone with a visible difference on their face or body has the confidence, support and opportunity to lead the lives they want.

We know from the people we support and through our research that being different in a society where there is such pressure to look a certain way is extremely difficult. We provide advice and support, we challenge discrimination, and we campaign for a society that respects difference.

If you wish to support Changing Faces in our work improving the lives of people with a visible difference across the UK, you can do so by:

Texting 'CFCF00 £5' to 70070.

CHANGING FACES

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