

Discovering Resilience: Supporting Children and Families with Facial Differences

By James Partridge, DSc, MSc, MA¹

Thank you for this opportunity. I congratulate you for organising such an event.

As you will already have noticed from my accent, I am from England. But the first thing you will have noticed, I suspect, before I even opened my mouth is that my face is scarred and different. But, do have a look, it's OK – I sanction looking, but not staring.

The answer to the question posed in this Panel Session: “*What’s in a face?*” is “A great deal”...

I didn't realise just how much, until I lost mine. For 18 years, I took mine for granted. Then I was severely burned in a car fire. My face was ruined and without a face, my life seemed destined for failure.

Faces are the canvas on which we paint our moods and feelings and so much more – and by looking at that canvas, other people can learn a lot about us. But faces are not just important ways of communicating with the outside world, but are highly significant for each of us as individuals too. As William Eiserman has said, when you look at your hands, they are “yours”, when you look at your face our self-image is intimately tied up with the face we project to the world.

Now 30 years on from my accident, I am very attached to this face and, much to my surprise and joy, I have more than I could have believed possible in my private life with a lovely wife and 3 lovely children. I have a professional background in health economics, teaching and farming.

About *Changing Faces*

In 1992, I set up and today I direct an organisation called *Changing Faces* in the UK working for a better future for children and adults with disfigurements to the face (and body), whatever the cause of the disfigurement – from birth, accident and disease (*Changing Faces* contact information at the end of the article). We are now dealing with over 1000 new enquiries every year from those affected by disfigurement and a similar number from professionals. We aim to work with and complement the work of all other specialists.

¹ Presented at *The Face of the Child: Surgeon General's Conference on Children and Oral Health* June 12-13, 2000, Washington, DC. Dr Partridge is Director of Changing Face Charity, UK.

Changing Faces is a not-for-profit raising about \$700,000 each year to run our programmes. We employ a 13-strong specialist team including 3 who work exclusively with children and families. Evidence underpins all our work – and we have established a University Research Centre led by my colleague, Dr Nichola Rumsey, a psychologist and international authority on disfigurement.

“*Changing Faces*” is not about surgery. We recognise the immense improvements in appearance that can be brought about by medicine and surgery but we also know their limitations. *Changing Faces* has a motto which tells our approach: “changing the way you face disfigurement” so that you can face it with confidence – whether **you** are experiencing it yourself, have a child who has become disfigured, or you are a professional in a medical, surgical or other professional discipline, or a teacher or a media person or an employer or anyone else.

One of our big insights is that while medicine categorises disfigurements into different specialties or disciplines, the reality is that in psycho-social terms, the children and adults affected all experience common challenges. The child with a cranio-facial condition faces very similar psycho-social challenges as a child with burns or eczema.

What’s it like to live with a different face?

This talk is about resilience. After my accident, I had to discover resilience somehow, but largely in isolation. My family and I (because disfigurement is a family affair) had to discover how to do it – largely by trial and error. “You’ll learn how to cope” was a frequent line from my health care team – even “you’ll have to learn how to cope”. I pointed out then that if I wanted to learn French, how to drive a car or bake bread or acquire many other skills, I could go to a specialist or read a book – but there was nowhere to go to “learn disfigurement”. Twenty years later, I wrote a book that was an attempt to fill that void: to explain what it is like and how to discover resilience.

Facial disfigurement from whatever cause is a challenge every day, as I soon discovered: being self-conscious in the extreme; a sense of “standing out in the crowd”; of being stared at; asked curious questions; treated as odd and different; being name-called and avoided. Those affected can detect our disadvantage in small subtle (but not unseen) acts of eyes turning away or turning down. Face-to-face interaction is essential to human beings even in our crazy high-tech world; if you look different, it is much more complicated.

And the challenge goes deeper too: we live in a society that places a very high value on appearance. We are conditioned through the daily bombardment of visual messages that “good” looks are passports to success in work, relationships. Looking different doesn’t get a good press. Add to these psycho-social challenges, the added burden of frequently being a patient, with all the family pressures, anxieties and hopes this involves.

For all these reasons, anyone who acquires a disfigured face needs to discover resilience – and the earlier the better. And their families need to, too. What I will try to do in this paper is to present our model of resilience and describe the role of health care in its development.

What is resilience?

In a rather simple way, I take resilience to be the ability to take hard knocks, to weather the storm and to continue to value yourself despite it all. Can you discover it? I think you can but not as you would hidden treasure. Rather resilience has to be built up like stamina. What is more, lots of people can help you to cultivate resilience. And I think health professionals have a huge role to play in nurturing it.

Looking at my personal experience, what did I learn in the process of my recovery? I had a lot of things going for me (pre-existing confidence, high-ish IQ, supportive family), but it was not at all easy. On reflection, 3 things stand out as things that I had to do.

- I had to re-design my social skills so that I could manage the reactions of other people
- I had to re-write my inner script about difference: I had to debunk the idea that looking like I do means a second-class existence; looking different had to become OK
- I had to re-discover my self-worth: I found success in academic study, in sporting activity, and most of all, by finding friendships and love that were not reliant at all on my appearance – and through all this, my self-belief returned.

This three-dimensional framework is helpful for thinking about how people can discover resilience: individuals can be thought of as having three dimensions of resilience, like an egg – with an outside shell of resilient behaviour, a white of resilient thoughts and a yolk of resilient feelings. So resilience is made up of...

- behavioural resilience – the capacity to interact successfully and to cope with problem scenarios – the shell
- cognitive resilience – the capacity to talk to yourself in a robust and supportive way and to have a characteristically positive outlook on the future – the white
- emotional resilience – the capacity to feel good about yourself – the yolk

This “egg” framework allows us to look at each aspect of resilience separately though, of course, in reality they are all part of a whole. In considering each dimension, I will give you three small vignettes to illustrate our work and reflect on the role that health care professionals (and others, eg: teachers) can play in empowering resilience in children and families who are experiencing facial difference. The case studies deal with children with different disfigurements – but, as I have already said, their psycho-social concerns are very similar.

Behavioural resilience – the capacity to interact successfully with others and to cope with problem scenarios

I often say that the first months after re-entering the world from my burns unit were like going back to learning social skills in kindergarten. Everyone I met behaved differently to me – they seemed scared to look at me, ask me the wrong thing... embarrassed... Discovering resilience meant discovering initiative-taking strategies for putting them at ease. This has been the basis for a lot of our work...

Let me give you an example, a parent contacts us about their little boy, George, who was born with a very large and raised hairy naevus all over his face. At 8, the family decided to go for tissue-expansion to remove the birthmark. All went well... and the surgical result was excellent but George became depressed at school and within a few months was regressing.

Our assessment unearthed that George saw the surgery as a huge disappointment because he had thought the naevus would go completely when in fact, it had left major scars across his cheek, neck and forehead. On return to school, he had become very self-conscious and had had to face taunts from some older children – in place of “Hairy”, he was now called “Scarface”. He didn’t tell his parents because they were so pleased with the operations – he didn’t want to disappoint them.

This child had no skills other than his fists and shouting. What we did was to equip him with a few simple strategies, like a tool-kit, for dealing with difficulties. Two stand out: first, we showed him how to change the subject – “distraction” – so that he could shift the focus from himself to something else (eg: football/soccer, the teacher etc). Second, we worked on an assertive response to his tormentors which he could use – he decided on “My name’s not Scarface, it’s George”, and we worked with him to ensure that he said it with conviction.

Parents, too, need to learn initiative-taking methods to deal with the reactions of other people. We have produced a very practical guide for parents (“*My child looks different*”) – which describes how through their own actions, parents can model how they want their child to behave. But don’t assume that parents know how to do this with confidence. It is very easy for them to assume that the inevitable staring is hostile when actually it is just information-gathering. If they react hostilely, the child will learn to do this too.

As the child grows, the development of friendship skills and protective skills becomes increasingly essential. Transition to a new school is a time when these behavioural strategies are needed in mega quantities. Later, in the teenage years – as Kathy Kapp-Simon has said so eloquently – without the capacity to start conversations, for example, the child with a facial difference tends to “fringe” on their peer groups. Taking the initiative has to become second nature. We have a Reach Out programme based on a social skills video which demonstrates some initiative-taking strategies that work. It is being used, for example, at the Shriners Burn Center in Galveston in a weekend programme but can be run in other formats too (eg: 1-1).

So, the outer shell of the egg needs to be hard enough to resist the intrusiveness of others.

Health care professionals have an important role in nurturing this behavioural dimension of resilience and can

- ensure that parents have the advice they need to cope with the everyday curiosity etc.
- offer guidance on initiative-taking strategies, especially on how to deal with staring

Let me turn to what is possibly the most important aspect - the cognitive.

Cognitive resilience – the capacity to think and talk to yourself in a robust and supportive way and to have a positive outlook

The acquisition of a language and vocabulary with which to talk about disfigurement and difference is absolutely crucial. We often find that families have avoided the subject, because they feel that by treating their child “like everyone else”, everything will turn out OK. To the child, this may not feel so good, more like avoidance, guilt or embarrassment on the part of the parents... they never acquire the words – and of course, because their difference is not acknowledged or referred to, other people with differences are not referred to either, avoided.

An example: Billy is a 14 year old with a significant disfigurement from neurofibromatosis had been making no progress at school, truancy and bad behaviour had become entrenched. When Billy had first started at the school, three years ago, his parents had not wanted anything said about his disfigurement – understandably, they had wanted him to be treated just like everyone else. But the unforeseen result was that no-one had ever known with any confidence what to say when any other pupil asked a question or passed an unpleasant remark. It also emerged that some teachers had assumed that the boy must have some kind of cancer and were wondering when he would die. With the lack of straightforwardness, consistency and sureness of approach that resulted from all this ‘not knowing’, it seems that a culture of escalating insults and retaliations grew up – in which the Billy himself participated with gusto.

Over about 6 months, our School Specialist and others in the team have been working with Billy, his parents and both teachers and classmates in the school and I’m glad to say that the young man is about to go on a work experience placement with some confidence.

We enabled the parents and family to acknowledge the child’s difference and, very belatedly, to realise how to talk in the family about the condition and its effects. Billy himself explored what words he wanted to use – see our 4 booklets for teenagers, the first of which is called “*Looking different, feeling good*”. The second is entitled “What happened to you?” designed to enable teenagers to find out, to develop a vocabulary of their own and then to be able to answer the question with confidence.

Billy also made the huge discovery that other teenagers also have problems with their appearance – so he was not alone!

The other thing that was incredibly significant for this family was our decision to offer to put this family in touch with a man in his late 20s with the same condition who is married and thinking about a family. I stress that we did not just pick anyone with the condition, but we deliberately approached the best role model we could find from our lists. Meeting him was positively revelatory: the child and family realised that their thinking had been incredibly fearful about the future, understandably so. But it was possible to be more positive. It was possible to see strength in diversity and difference.

Health professionals also have an important role in the cognitive dimension and can...

- encourage the family to use an informed and shared vocabulary and language about the condition
- build thinking habits that see the future with optimism, the self-talk that says “this is do-able” and optimistic, and to be tough enough to drive away the words of others.

Emotional resilience – the capacity to feel good about yourself

Last but at the heart of the matter, is emotional resilience. The yolk feeds on the white and the shell and from the yolk comes new life.

The sadness associated with disfigurement need not persist. If what parents and family do around the child is positive, an emotional strength and self-belief can build.

A family contacted us some time ago having just discovered that the miracle surgery that they had believed would remove their little girl, Emily’s hemi-facial microsomia, was not going to be as successful as they had hoped, and that it was to be delayed for many years. They were devastated and at their wits end. It seemed to matter so much.

As we got to know the family, we realised that the little girl’s chances were being somewhat undermined by the parental disappointment. She had a good range of intellectual abilities, hobbies and friends and was particularly showing promise at tennis (which is something that one parent coached professionally). We believed that the nurturing of the child’s talents needed to be more recognised by the parents.

Once this was very gently put to them, they grasped it with both hands and the results have been wonderful to date. Not only have they started to celebrate the child’s skills themselves, they have also ensured that her school was well-informed and could really support her.

Emotional resilience is probably the hardest to define and most tantalising to develop but health care professionals can

- encourage the family to nurture their child’s talents, abilities with belief
- ensure that follow-up is active after bad news has been imparted

It goes without saying – but I will say it any way – that much of the building of resilience has to be done via the parents who can then influence their child. As the child goes through their adolescent years, they gradually become independent in thought and action, so the focus has to be more on them as individuals. We should also observe how very important it is to support the whole family so that all members, including siblings, discover resilience.

An article about our work with children and families will appear shortly in the journal *Clinical Child Psychology and Psychiatry* – by Veronica Kish and Richard Lansdown; our booklets etc. can be

obtained from the Changing Faces office or visit our website www.changingfaces.co.uk to place an order.

Investing in incubation

Discovering resilience is not something that happens in a eureka! moment – but it can be found. The key points are to develop a shell of social skills for the hard knocks, a white of positive self-talk for the heavy weather, and a yolk of self-belief to enable the child to value themselves through it all.

We are convinced that our approach to psycho-social rehabilitation can be embedded in clinical processes. We are encouraging health care to develop resilience-building interventions to address the psycho-social needs of their patients.

Gestating an egg takes a long time – and *Changing Faces* is not a magician able to pluck an egg from nowhere. Nor are we hens! But we believe that health care systems can be incubators. We are demonstrating that these psycho-social interventions to build resilience are non-expensive but highly cost-effective in quality of life terms – and, we believe, in reducing future resource use of health care resources. There are many ways. For example:

1. The recent decision by the UK Government to ensure that a psychologist is a core member of the multi-disciplinary team delivering care for children with clefts is another step in the right direction. *Changing Faces* will work closely with Dr Nichola Rumsey in developing training courses in this area for psychologists.
2. UK surgeons are realising that more can be done – in Belfast, a plastic surgeon has led the drive for a “central disfigurement referral unit” to be developed.
3. *Changing Faces* is starting to develop training programmes on psycho-social issues for other professionals such as nurses – starting with cancer and burns. We hope to make these courses accessible through our website in the future.

Conclusion

Let me end with a quote from a mother: “I’d never met anyone with a disfigurement until I met my son”. Most people have no previous experience. Their uncertainty will show in their not knowing where to start, how to talk about it, how to deal with other people – all normal anxieties.

Resilience is a critical characteristic for all children to live fulfilled lives. For those who have facial differences, it is even more important. Health professionals can play a key part in strengthening the shell, bolstering the white and colouring the yolk for these children and their families...

Recommended further reading:

Clarke, A., (1999) Psychosocial aspects of facial disfigurement: problems, management and the role of a lay-led organisation. *Psychology, Health & Medicine*, 4, 2, 127-142.

Partridge, J.(1990) Changing Faces: the Challenge of Facial Disfigurement, Penguin (now only available from Changing Faces)

Partridge J (1998) Taking up Macgregor's challenge: the work of Changing Faces. *Journal of Burn Care and Rehabilitation*, March 1998

Robinson, E., Rumsey, N. and Partridge, J. (1996). An evaluation of the impact of social interaction skills training for facially disfigured people. *British Journal of Plastic Surgery*, 1, 49, 281-289.

Strauss, R. "Only skin deep": Health, Resilience and Cranio-facial care. (paper given at Panel on "Blessings in Disguise: The experience of healthy adaptation to cleft palate and cranio-facial conditions", American Cleft palate/Cranio-facial- Association Conference, April 1999)

Zephaniah B. (1999) Face, Bloomsbury, London.

The self-help resources (booklets, videos etc) referred to in this article are available via Changing Faces. Please contact: Changing Faces, 1 & 2 Junction Mews, London W2 1PN, UK.

T: 44 20 7706 4232, F: 44 20 7706 4234, E: info@changingfaces.co.uk

Acknowledgements

I would like to thank my colleagues, Alex Clarke, Clare Cooper, Jane Frances and Kathy Ross, and Nichola Rumsey for their help in the development of these ideas.

James Partridge, DSc, MSc, MA

29.7.2000