



Empowering People with Facial Difference: Building resilience through non-medical intervention

by Samina Kiran Tariq
April – June 2012



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A Winston Churchill Memorial Trust Fellowship Report

Abstract

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Having a facial difference brings many challenges one of the main one's being dealing with the reactions of others. These vary from intrusive, judgmental stares and comments to emotive gestures of pity or disgust.

Those of us with a facial difference risk developing negative self identities if we do not have the appropriate support and skills to manage the social oppression we experience.

My personal experience and professional interest as a youth worker made me want to research this area further by identifying examples of good practice in supporting people with a facial difference to develop their resilience and build positive self identities. Central to this was listening to the experts – people with a facial difference on what helps them build their resilience.

As a Winston Churchill Travel Research Fellow I travelled to the USA and Canada where I interviewed many inspirational people with a facial difference and their families. I interviewed staff from prominent organisations that provide a service to people with a facial difference and their families.

The research found the key to supporting people with a facial difference is to challenge the assumption that having a facial difference is a taboo subject and instead create opportunities for people with a facial difference to offer peer support, raise public awareness and promote a positive portrayal of people with a facial difference in all aspects of society.

This research report increases our understanding of the importance of non-medical interventions to support people with a facial difference to build their resilience and provides lots of examples on how such support can be given.

Acknowledgements

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My gratitude to everyone who has contributed their time, shared their experiences and thoughts on the research topic in particular I would like to mention: Doug Auld (Artist), Cassandra Aspinall (Seattle Children's Hospital, Senior Social Worker), JR Martinez (War Veteran, Actor & Motivational Speaker), Debbie Oliver (AmeriFace, Chief Director), Randy Pielsticker (AboutFace, Camps Coordinator), David Roche (Inspirational Humorist, Performer & Inspirational Speaker), Matthew S. Joffe (Educational Therapist), Scotty Stevens (Camp Korey, Assistant Camp Director) Ann Mason & Dr Solomonson (St John's Health Centre, Social Worker & Plastic Surgeon) & Farah Sheikh (Toronto's Hospital for Sick Children, Social Worker).

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This report presents me with an apt opportunity to thank all the professionals involved in my care.

Thank you ...



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About the Winston Churchill Memorial Trust www.wcmt.org.uk

Each year the WCMT awards 100 Travelling Fellowships to British citizens for a wide range of projects. Fellows travel overseas to bring back knowledge and best practice for the benefit of others in their UK professions and communities.

This report is in fulfilment of my responsibility as a Fellow and presents my views and does not reflect those of the Winston Churchill Memorial Trust.

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Introduction

The charity Changing Faces¹ estimates about 450,000 people living in the UK have some kind of facial difference (2001). The term facial difference is used to describe people like myself who have a face that looks significantly different to the conventional face. For example a person with a facial difference may have a mark, scar, burns, asymmetry or paralysis to the face.

A lot has been written about the significant relationship between appearance and self image in particular how we see ourselves is heavily influenced by how others see us or how we how we think they see us (Coleman and Hendry 1999; Heaven 2001).

There is some evidence to suggest that people with facial difference experience particular challenges and difficulties in developing a positive self image due to the psychological losses that are caused from having a facial difference and associated functional limitations that may arise because of it (Newell 2000; Rumsey, Clarke and Musa 2002).

"The cruellest legacy of my acne is the profound conviction that I'm different to others, that I'm unworthy, that I can never hope for ordinary happiness ... anyone meeting me for the first time must be filled with repugnance and pity." Richardson, cited in Rumsey & Harcourt, 2004, p.85

From a biomedical perspective, medical intervention is seen as holding the answers to the problem experienced by the person with the facial difference hence, follows a series of treatment to help the person appear more 'normal'.

For those of us who have received medical care and value it, we are also only too aware of its limitations; at which point we are encouraged to 'cope' with our facial difference. James Partridge reflects on how in the early days of his accident he was on a number of occasions told "You'll have to learn how to cope", (2000, p.2). There may be help on hand from psychologists and therapists to help the person cope with their appearance.

As a person who acquired a facial difference at the young age of nine and now 32; I am forever surprised by the condescending assumption that people with facial difference struggle to 'cope' with looking different; when in actual fact the difficulty we experience arises largely from other people's ways of coping with the way we look.

On a daily basis people with facial difference are managing the social stigma which perceives a flaw or blemish as undesirable that needs to be corrected, and permits 'normal' people to stare and comment. We are bombarded with socially constructed and unrealistic images of what is considered beautiful and the negative representation of people with facial difference risks leaving people with facial difference with the belief that the root cause of all our problems is our facial difference which heightens the risk of us developing poor self image and adopting a negative identity.

Resilience is a complex concept as its meaning and usage varies within social theory. However, Masten et al, (1990, p12) provide a helpful explanation of the term:

(T)he process of, capacity for, or outcome of successful adaptation despite challenging or threatening circumstance.

In the context of resilience for people with facial difference, the term has generally been understood to mean the strength of the individual with a facial difference to manage the psycho-

1. Changing Faces is a UK based charity giving support and information to people with a facial difference. The charity was founded by James Partridge in 1992, he has a facial difference himself. www.changingfaces.org.uk

social trauma of looking different and the affect it has on their self esteem. (Kent and Thompson, 2002).

Much focus of researchers and the media is focused on the individual's ability to manage the psycho-social trauma of looking different. It can be suggested that from the outset facial difference is perceived as the root cause of tragedy and trauma for the individual and in itself reinforces the negativity associated with having a facial difference.

Learning from the social approach to disability, it is important to remember that beauty and attractiveness are socially constructed and can be oppressive values for those of us that do not conform. Through my research I want to shift the focus of people and research away from seeing people with facial difference as being tragic and emotionally unstable and instead highlight that living with a facial difference brings with it the same challenges that any marginalised group face and therefore the methods to challenge this social oppression lies in what role society is ready to play to invest in change. The key to change also lies in listening to what people with a facial difference have to say about their experiences and what non-medical interventions they would find helpful in building and strengthening their resilience.

“If there was a newsreader with a disfigurement this would go along way towards normalising the condition. People never thought you’d see a black newsreader and now the most famous newsreader is black!”

James Partridge, 'n.d.'

This is the approach I have sought for myself and adopt as the basis of my work with the young disabled people I work with.

In February 2012 I was afforded the opportunity to combine my research interest in the area of facial difference and resilience with my passion to travel by the Winston Churchill Memorial Trust (WCMT). The WCMT awarded me a travel research bursary for a period of 10 weeks in North America. This is my research report as a Winston Churchill Fellow.

My research report begins in Section Two where I share the aims and objectives of my research and explains how I undertook the research. Section Three presents the five key findings from my research and also gives an insight into my travels. Section Four proposes seven recommendations on how the UK can support people with a facial difference to build and strengthen their resilience. The report ends with a short summary in Section Five on the difference travelling makes.

Also available at the end of this research paper as appended material is a list of all the people and organisations I met for the purpose of this research.

2. Travelling to make a difference

2.1 The purpose of my travel fellowship

The WCMT approved my ten week research proposal to travel to North America with the aim of identifying best practice examples of supporting people with facial difference to strengthen their resilience and develop positive self identities. My research title: *Empowering People with Facial Difference: Building resilience through non-medical intervention.*

2.2 The difference I was looking for

- (i) **Good practice examples:** explore how non-medical interventions such as peer support and burn survivors' camps support people with a facial difference to build their resilience and positive self identities.
- (ii) **Voice to people with a facial difference:** for people with a facial difference to share their experiences of what has helped them build/strengthen their resilience.
- (iii) **Role models:** identify role models who have a facial difference, and are successful, inspirational figures who have embraced their identity.

2.3 The difference travel research would bring

I would like to shift the focus of seeing people with facial difference as victims and instead highlight that we experience many challenges some of which can be surmounted through non-medical interventions and a better representation. With this in mind I hope the difference my travel will bring is:

- (i) To present good practice examples for those looking at what types of interventions support people with a facial difference to strengthen their resilience and develop positive self identities. In doing so, make the case for the UK to have more non-medical intervention programmes.
- (ii) For people with a facial difference it will provide a motivational and informative read that will inspire them to find pride in their difference and embrace their facial difference as part of their identity.

2.4 My research methods

Some of my research itinerary was planned before I left the UK, so I had already made some great contacts within the USA and Canada and once there I found the people I approached very open and receptive. My principal research method was informal interviews and some participant observations. I attended conferences, visited organisations that provided a service to people with a facial difference such as camp sites; where I met with the staff and the service users. I met with hospital-based staff and arranged conference calls when I was not able to meet with people in person. I met with inspirational people with a facial difference whom I interviewed and some I even shadowed as they worked.

The key was to listen to the experiences of people with a facial difference and bring back their recommendations.

2.5 Where I travelled to

For my research I travelled to North America. In the USA I visited California, Las Vegas, New York, Seattle and Washington. In Canada my research took place in Vancouver, Roberts Creek and Toronto.

3. Key research findings

The following section presents the key research findings from my travels under four broad themes.

3.1 The difference between facial disfigurement and facial difference

On day two of my travel research I attended the Cleft Palate Foundation's² 2012 Connections Conference for people with a personal experience of facial difference and their families, in San Jose.

Whilst networking I met with Debbie Oliver a parent of a young woman born with a cleft palette and also the Executive Director of AmeriFace³. AmeriFace is a charity that provides educational and emotional support to people with a facial difference and their families – in particular for parents and carers. As Debbie explained her work a key word stood out – she used the word 'facial difference' to describe the service users she supported. I had not heard the use of the term before to describe people like myself who through burns, cancer or birth marks had a face that looked significantly different to that of others. As I visited stalls that day and picked up their leaflets and spoke to other professionals and families they all seemed comfortable to identify as being or having someone within their family with a facial difference. There appeared to be a strong sense of community amongst the attendees.

I began thinking of the term Debbie had used to describe people like me and how it compared to the term facial disfigurement which is widely used within the UK. My interest in comparing the two terms was based on how they made me feel; the term facial disfigurement always made me feel uncomfortable with negative connotations almost to suggest that someone like me was abnormal, incomplete, thus unvalued. If we are described using terminology that is negative then we will avoid using it and when it is used it will make us feel negative about ourselves. It is not a term that evokes positive feelings but labels us again and continues to stigmatise. In contrast the term facial difference felt respectful and appropriate. It is a term that subverts the negativity associated with looking different and instead asserts a sense of acknowledgement of looking different and also a positive sense of recognition and pride. In doing so the terminology in itself challenges the stigma associated with looking different.

I felt compelled to rethink the use of the term facial disfigurement in my research title and research as a whole. I was pleased to find the WCMT would support my request to want to change the use of the word 'facial disfigurement' in my report title to 'facial difference'.

3.2 The value of peer support

"Peer support is a system of giving and receiving help founded on key principles of respect, shared responsibility, and mutual agreement of what is helpful. ... it is about understanding another's situation empathetically through the shared experience of emotional and psychological pain." Mead, 2003, p.1

When visiting Canada and the USA I was able to see the diverse and creative ways in which peer support was available and the positive impact it was having on the lives of people with a facial difference.

2. Cleft Palate Foundation is a US based organisation whose mission is to enhance the quality of life for individuals affected by cleft lip and palate. www.cleftline.org.

3. www.ameriface.org

3.2.1 Befriending and mentoring

Non-profit organisations such as the **Phoenix Society**⁴, as well as hospital-based support groups such as those offered by Toronto's **Hospital for Sick Children**⁵ offer opportunities for people with a facial difference to support and empower one another. Whether it's through formal mentoring programmes or social groups, camps and conferences, all are avenues through which people with a facial difference develop a sense of community in which they are able to support and encourage one another, raise aspirations by being encouraged through a peer's success. For example the Phoenix Society run a number of well developed and invested programmes for burns survivors. Amongst some of their great peer support programmes are the annual Burns Conference that is attended by people from all over the world and SOAR (Survivors Offering Assistance in Recovery) peer support programme.

I was particularly impressed by SOAR as it is an example of the high standards the Phoenix Society work towards. Potential volunteers go through a screening process which involves burns survivors making an application to become a mentor and are interviewed. Volunteers are then supported to develop their skills through a training programme after which they are matched with a peer whom they support. Furthermore, the programme is evaluated. Volunteers are linked up to a burns unit within their area. The programme is growing momentum amongst hospitals, across the US and Canada, demonstrating how successful a programme it is.

I observed that through the befriending and mentoring opportunities people with a facial difference were active, movers and shakers and in doing so challenging assumptions that people with a facial difference are passive, tragic or helpless.

Many people with a facial difference may be the only person in their family or community to have a facial difference (with the exception of those born with a cleft lip and palate). Therefore it can at times be difficult for a person with facial difference to share their worries and seek advice from their family and friends; fearing they may cause those closest to them to get upset or that they may be misunderstood and further stigmatised. Moreover, there are some life experiences that they will simply not have in common and be able to relate to. In such circumstances, being able to meet and speak to other people with a facial difference has the potential to positively transform lives.

I had my own experience of befriending when I was in the process of preparing for my interview with the Winston Churchill Memorial Trust. I had contacted David Roche⁶ a well known motivational speaker with a facial difference, based in Canada. I contacted David with a view that was I to be successful, I would like to meet and learn more about his work. At the same time, I felt ridiculous that I had not been awarded the Fellowship and yet was emailing and

“Just to know there are people out there that understand has been a true blessing.”

*Burns survivor,
Phoenix Society*

4. The Phoenix Society for burns survivors and their families is a US based non profit organisation; dedicated to empowering anyone affected by a burn injury through peer support, education and advocacy. www.phoenix-society.org

5. Social Workers based at the Burns Unit in Toronto's Hospital for Sick Children (SickKids) organise monthly events for children and young people affected by burns as well as family events. www.sickkids.ca

6. David Roche is an adult with a facial difference. He is a motivational speaker, inspirational humanist.

skype calling David for his advice and guidance. However, I found David to be supportive and encouraging.

It was at the Cleft Palate Foundation's Connections Conference that I finally met David and his wife Marlene in person. I also had an opportunity to participate in one of their **storytelling workshops** along with other people with a facial difference. I was pleasantly surprised by how openly and honestly David talked about his experiences of growing up with a facial difference; it was emotive, funny and insightful. The most interesting thing was reflecting on how David's storytelling had put most of us participants at ease to talk about our own experiences and in doing so I felt we were accepting a part of our identity that for long had been seen as a problematic area to discuss in an open forum.



David, Marlena and I at the Connections Conference

3.2.2 Virtual forms of support

It was interesting to see how popular virtual methods of support were for people with a facial difference. Organisations such as the Phoenix Society and AboutFace⁷ offered numerous virtual support methods such as chat rooms, forums, facebook and conference calls that could be accessed by people from the comfort of their homes.

It was during my stay in Roberts Creek that David Roche and I decided to see what a virtual support forum had to offer people with a facial difference. We became aware that AboutFace were holding their monthly conference call which anyone with a facial difference could book onto through their website. John, a trained AboutFace volunteer with a facial difference, facilitated the virtual forum. It was interesting that none of us were able to see one another and yet the issue of our appearance was what had brought us all together.

The agenda for discussion was left open for us all to decide and a male caller was particularly keen to share his experience of discrimination taking place at his work and the distress this was causing him. He reported feeling isolated and having no support. By the end of the call, he felt he had some options to try and address the discrimination and also would consider attending a residential organised by AboutFace for adults with a facial difference later that month. After the call, David and I reflected on how helpful and supportive this method of support was. We were able to relate to each other's stories and share approaches on how to manage some the challenges and difficulties experienced by our peers.

“Be part of the world as opposed to watch the world going by.”

Matthew S. Joffe

3.2.3 Camps

In **Seattle** I visited **Camp Korey**⁸, a designated camping site for children and young people with childhood illness or a serious medical condition. Scotty Stevens, the Assistant Camp Director, showed me around the camp facilities and shared more information. The Camp programmes run over the holiday period

“Being made to feel part of a group makes you feel confident.”

Jack, former Camp Korey camper and now volunteer

7. AboutFace is a non profit organisation based in Canada that provides emotional, peer and social support, resources and educational programs to individuals with a facial difference and their families www.aboutface.ca

8. www.campkorey.org

and tend to be specifically for children with a similar medical condition, for example they may have a week long residential for children with cancer or for children with a facial difference. Camp Korey has its own website and children can attend by simply registering their interest (with parental consent). Furthermore, they run events for families too. It was really interesting to learn how closely the **Seattle's Children's Hospital** and Camp Korey staff worked to coordinate and support children and young people to be able to attend. Staff at the children's hospital promoted the camp with patients and some of the doctors, nurses and social workers volunteered their time at the camp offering more specialised support to any child staying at the camp. It was refreshing to see this type of interagency working that benefited the service users. I had the opportunity to speak to a former camper called Jack who informed me that the camp was ultimately about having fun and what helped make it so was not to have to worry about looking different, bullying or having to explain what had happened to them. Moreover, it was the feeling of being accepted and included amongst the campers which made Jack feel confident. Although too old to return as a camper now, Jack had arranged to return as a volunteer with the aim of being able to offer peer support to the younger campers.

I left Seattle, with a great enthusiasm for what camps had to offer children and young people but it was when I met with **AboutFace** in **Toronto** that I was able to appreciate that camps offered adults with a facial difference as much purpose as they did to the young.

AboutFace is a Canadian charity that provides emotional, peer and social support, resources and educational programs to individuals with a facial difference and their families. They also run camps for children, young people and adults with a facial difference. Randy Pielsticker, Camp Director and also a person with a facial difference, is a great advocate for the importance of outdoor recreational activities as a means of developing self-esteem. Randy felt that when campers overcome their fear of heights or push themselves out of their comfort zones they learn to trust themselves, their abilities and the adrenaline takes them to new heights. The sense of achievement and self confidence they achieve at camps can be transferred to other areas of their lives too.



Randy and I at the AboutFace office in Toronto

My research into the benefits of camps for people with a facial difference of all ages has led me to believe they offer a unique life opportunity to:

- socialise in an environment in which they simply blend in as opposed to stand out
- form friendships without being worried of having to explain what had happened to them or fear of bullying
- share experiences and discuss some of the challenges related to growing up with a facial difference with people who can understand
- gain motivation and support from their peers
- older young people had a role to play as peer mentors
- develop their self confidence.

3.3 The role of the family

A key factor to how parents and other family members react to someone in their family having a facial difference is how it was acquired, for example if it was an accident or a hereditary condition, in which case the families response can vary considerably. An added dimension is financial strain caused by the need for health insurance that is required in the USA and Canada. It was beyond the scope of my research to explore the complexities of these issues but what I was able to observe was the importance of the role of the family in supporting people with a facial difference and what factors contributed to facilitating this.

I met many inspirational people with a facial difference and the majority of them related how their families were key in laying the foundations of their resilience.

I was impressed by the number of agencies that existed to support parents, carers and families to understand their child's condition. For example, AboutFace had some excellent resources, ranging from leaflets, support groups and toolkits that took parents through the various life stages to help them prepare as well as lay to rest some of their anxieties and answer questions. The information was informative and written by people who had personal experience. I found all the literature I reviewed factual and positive.

“Wonderful parenting exposed me to the world and the world to me.”

Matthew, S. Joffe, adult with a facial difference

Furthermore, I felt the USA and Canada had lots of examples of professionals from various backgrounds working in partnership to provide holistic support to the families of people with a facial difference as well as the person concerned.

For example, when I visited **Saint John's Health Centre's Cleft Palate Unit**⁹ in Los Angeles, I was impressed by the resident multiskilled team working together to support the family. You had social workers working alongside speech therapist and surgeons, amongst other key practitioners. Seattle's Children's Hospital had a similar setup; furthermore, they were aware of organisations that could support the families beyond the realm of the hospital, for example the staff at the Seattle Children's Hospital had a great working relationship with Camp Korey staff.

Many of the parents I spoke to reported feeling they had a good source of support to help them understand and respond to their child's emotional needs as well as their own.

The Cleft Palate Foundation's Connections Conference I attended in San Jose was a great example of how parents were supporting one another. Parents were on presentation panels speaking about their experiences along with their children and they also attended workshops. By sharing their experiences they reported feeling listened to and that they were not alone in their experiences. Furthermore, parents with young children who were at the beginning of their



Panel of parents and young people with a facial difference speaking at the Connections Conference.

9. www.newstjohns.org

journey felt reassured by seeing teenage and adults with a facial difference speak about their life experiences confidently.

It appeared that parents, carers and siblings were being offered support to help them effectively support their family member with a facial difference as well as having means through which address some of their own concerns. It felt like some of the stigma associated with facial difference was being challenged by not feeling alone and isolated.

3.4 A positive portrayal of people with a facial difference

3.4.1 State of Grace

Traditionally, portraits have been regarded as a realm of the beautiful who are seen as being 'fit for a portrait'. In crude contrast, people with facial difference have traditionally been displayed as freaks, objects of disgust, pity or laughter and certainly not regarded as 'fit for a portrait'. You can then appreciate my shock at coming across a portrait of a man with burns to his face – I was immediately gripped. I was moved by the work and just had to meet the artist behind the portrait – Doug Auld.



Portrait from the 'State of Grace' series.

I met Doug in his studio in New Jersey where on the back wall I saw the portrait that had led me there displayed amongst several other large scale portraits of adolescent burn survivors. As I spent some time staring at the portraits I felt each one had a presence, the self image of the person was proudly presented to those staring. The portraits gave me a sense of collective identity and I was drawn in by a sense of community; we shared a common experience and yet had never met, but I could appreciate what they would have gone through, relate to their feelings and identify with their scars.

I learnt that all the portraits were part of a series called State of Grace¹⁰. In 2002 Doug approached his local burns unit at Saint Barnabas Medical Centre with a proposal to paint ten portraits of burns survivors with the aim of challenging the stigma of having a facial difference and perceptions of what beauty is. In Doug's view:

"If people have a chance to gaze without voyeuristic guilt at the disfigured, they may be more likely to accept them as fellow human beings ..."

Doug's inspiration for the project comes from a distant memory from thirty years ago when he remembers staring at a young burns survivor 'in shock and disbelief'. Doug's reaction was typical to many people's reactions but on reflection he was uncomfortable with his behaviour that day – aware that he must not be the only person the young girl would have experience of reacting in such a way. Doug wanted to use his work to help explore notions of outer and inner beauty; social consciousness and resilience; which he was able to achieve through the State of Grace project. The message from the portraits series has received prominence across the USA and in June 2006 *The New York Times* featured the project in a front page story of their Metro section.

10. www.dougauld.com

By the end of our meeting I was able to appreciate how the State of Grace project gives people without a facial difference an opportunity to stare free of guilt, make sense of their own emotions and fears around facial difference and for people with a facial difference the portraits are a symbol of survival, and pride, as the person in the portrait boldly stares back at the gaze of strangers.

The State of Grace message is a powerful one for people with a facial difference and those without and portrays the diversity of human beings which has for so long been ignored in portraits.

3.4.2 JR Martinez: War veteran turned actor and motivational speaker

The portrait I referred to earlier is that of Jose Rene ‘JR’ Martinez.¹¹ I had heard about JR through my friend David Roche who was aware of my WCMT research interest and thought I may be interested in speaking to him. Due to his busy schedule I was unfortunately not able to meet JR in person but a conference call was arranged thanks to his manager.

In 2003, JR sustained severe burns to over 34 percent of his body while serving as an Army infantryman in Iraq and just five years later he became an actor and motivational speaker.

I was deeply impressed and inspired to find JR had been acting in one of the lead roles on ABC’s popular daytime drama All My Children and more recently the winner of the hugely popular talent contest for celebrities in the US – Dancing with the Stars, Season 13. JR’s success on mainstream US television has helped counter the negative portrayal of people with facial difference which for so long has focused on tragedy, adversity and loss.

JR shared that his road to recovery was not easy but a motivating factor in the early days was meeting another burns survivor who helped him understand that he was not alone in his experience and the comfort of being able to talk to someone who understood; which helped him get through a difficult period in his life by motivating him to do something positive with his life.

JR’s success is down to him wanting to achieve and he does this by setting himself multiple goals. Positive life experiences and his achievements have all helped him strengthen his resilience.

Rather than passively conforming to the stigma of having a facial difference, JR made a conscious decision to assertively take control of situations where strangers were staring or passing comment about his facial difference and using the opportunity to educate people. JR has travelled around the US speaking about his experiences to corporations, veterans groups, schools and other organizations to educate people on accepting difference as normal and inspiring people with a facial difference to feel confident in who they are and achieve their dreams; he wants to ‘use my experience to help others’.



JR Martinez

“We live in a visual world and the way I see it is, is that when people stare for a few seconds it’s down to curiosity and it’s up to me to turn it into a minute of education.”

JR Martinez

11. www.jrmartinez.com

By speaking to JR it was clear to see how his resilience stems from having a sense of responsibility to help others as he is able to appreciate the inspiration that has led him to achieve all the great things in his life.

3.5 Finding role models

Throughout my research travel I met many inspirational people with a facial difference and I have mentioned most of them in this research paper.

The role models came from all walks of life, had different occupational backgrounds and different life experiences; but all of them demonstrated how people with a facial difference can live happy and successful lives. They are who they are not despite their facial difference but partly because of it.

They have inspired me and I hope they have inspired you.

4. Recommendations

There were some similarities between the kind of support available to people with a facial difference living in the UK and North America but I was also able to identify examples of good practice which would be exciting to see happen in the UK. I have proposed seven recommendations which I think would benefit people who have a facial difference to feel empowered.

4.1 Getting the terminology right!

- For the term facial difference to be used by health professionals, academics and society in general to describe someone like me as opposed to the term facial disfigurement.

4.2 More opportunities for peer support

- Opportunities for people with a facial difference to befriend and support one another. For example, through virtual forums and chat rooms, or camps, support groups and social events. These need to be well publicised.

4.3 Personal development opportunities

- I would strongly recommend for there to be specific personal development programmes for people with a facial difference and where possible for these to be led by people with a facial difference.

4.4 Support for families

- Opportunities for parents who have a child with a facial difference to meet other parents who have a similar experience; giving them the chance to discuss issues that concern them, share positive stories as well some of the challenges they experience and how they may be able to address these. This can be one-off meetings or continued support through a support group, informal coffee mornings that meet on quarterly basis.
- Workshops for parents to raise their awareness and confidence of what support is available to them as well as workshops delivered by people with a facial difference so that parents can see first hand the potential their child has.

4.5 Effective partnerships

- Professionals working with people with a facial difference to adopt an empowering approach. This can be achieved by very simply listening to the voice of the person and through accessing training.
- Opportunities for professionals who work with people with a facial difference such as NHS staff, social workers and school-based staff to network so that they have a better understanding of what support may be helpful to people they work with and also to be able to provide more holistic support.
- Networking opportunities where professionals and people with a facial difference network together.
- Better interagency working that takes a holistic approach to the needs of the person with a facial difference.

4.6 A positive portrayal of people with a facial difference

- The representation of people with a facial difference needs to become more positive. The media can use their influence to challenge the myths and stereotypes associated with having a facial difference by presenting people with a facial difference positively and in more mainstream programmes.
- The media in England have begun to take positive steps in this area notably through the coverage given to Katie Piper and the Katie Piper Foundation¹² and they can build on this by giving a wider representation of people with facial difference to present the diversity.
- Equally schools are in a great position to challenge misconceptions by implementing programmes that educate students.
- Prominence of people with facial difference as role models – Katie Piper and James Partridge are great role models but the more we have the better.

4.7 Investing in change

- More funding support for organisations such as Changing Faces, the Katie Piper Foundation and hospital burns units so that they are able to offer coordinated and nationwide opportunities for people with a facial difference to meet, befriend and offer peer support. Such programmes need to be well invested in by first training those interested in befriending or volunteering so that the quality of support being offered is not compromised.

12. Katie Piper Foundation is a UK based charity that was set-up by Katie Piper, a former model who received burns to her face following an acid attack. The charity aims to make it easier for burns survivors to live with their burns by offering self-esteem building workshops, peer mentoring and other cosmetic related treatments.
www.katiepiperfoundation.org.uk

5. Closing Summary: The difference travelling makes

“Twenty years from now you will be more disappointed by the things you didn’t do than by the ones you did do. So throw off the bowlines, sail away from the safe harbour. Catch the trade winds in your sails. Explore. Dream. Discover.” Mark Twain

I remember hearing about the WCMT fellowship back in 2001 when I was completing my undergraduate degree. Back then it was a dream to travel, to explore the world around me but as a disabled young woman I gave myself a hundred and one reasons for this not being possible. It took me over 10 years to fulfil that dream and I hope that other young disabled people will not take as long. I hope they find this report inspiring and informative and more importantly make the most of opportunities such as those offered by the Winston Churchill Memorial Trust.



Me overlooking the Grand Canyon.

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Appendix: List of some of the key people who contributed to the research

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**Empowering People with Facial Difference:
Building resilience through non-medical interventions**

By Samina K. Tariq

April – June 2012

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A Report for the Winston Churchill Memorial Trust www.wcmt.org.uk



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