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**Authors:** R. E. Peacock, PhD student; Dr A.R. Sargeant; Professor N Small, all from Faculty of Health Studies, University of Bradford

## Facial difference, consumer culture and being 'normal'

### Introduction

The face is not the property of an individual; it is a key part of our communicating body. It is performed, in social interaction (Goffman, 1982) and seen and responded to within historicised and gendered ideals of the normal and of beauty. The normal and the beautiful have a particular resonance in a visually mediated consumer society, "looks matter". But more than half-a million people in the UK have a significant disfigurement to their face (Changing Faces, 2007). This chapter explores the way facial difference illuminates debates on bodily representation. It explores how people living with visible facial difference invoke discursive formations of disfigurement (Garland-Thomson, 2009). It asks how we encounter and respond to facial difference and examines how close personal relationships can offer a source of support. The chapter contextualises the relevance of the face for communication and then examines implications for social selves in personal communities. Seventeen people living with visible facial difference were interviewed as part of a PhD study and interview extracts illuminate different aspects of the aesthetics of inclusion. The study explored patterns of personal communities and the interplay with lived realities of people with visible facial difference. The quintessentially embodied nature of this sort of difference illuminates the experience of the cosmopolitan. Cultural cosmopolitanism requires an ability to empathize with others and to celebrate difference and diversity (Held, 2002). It requires that we have the semiotic skills to interpret images of others (Urry, 2000). We can see in both the self-perception of people with visible facial difference and in their accounts of the responses of others to them a continuing challenge to achieving cosmopolitanism. It is hard to look past the face.

### Bodily representation

Images of the face, alongside idealised notions of self-transformation with the aid of surgery, style advice and appearance make-overs enable a presentation of the self that communicates confidence. These images are widespread in consumer society (Featherstone, 2010). Ideals of beauty can be historicised and relativized with contemporary variants positioning beauty as something that can be bought, modified or fixed (Synnott, 1988). People with visible facial difference have long lived alongside the promise of plastic surgery and its close relation, cosmetic surgery. Plastic and reconstructive surgery can save lives, improve function and offer a promise of restoring faces closer to facial normality. Cosmetic surgery on the other hand is better known for its promise to smooth over processes of ageing. A celebrity focussed, visual culture has been implicated in producing rising

levels of body dissatisfaction among 'normal' people (Rumsey and Harcourt, 2012). It can, however, be viewed as making more commonplace the (surgically) changed appearance, questioning ideas of the 'natural' and thereby increasing interest in understanding the dynamics of altered appearance or modification of the body (Featherstone, 2010)

Images of facial differences are present in fairy tales, literature, films and on television in the form of make-over shows, dating games and documentaries of facial reconstruction. A range of character positions make apparently physiognomic linkages between visible disfigurement and moral judgements, positioning scarred or damaged faces with 'bad' or 'damaged' character (Twine, 2002; Partridge, 2012). Although the 'science' of physiognomy has had its day, it lives on culturally through these representations which serve as heuristic devices linking meanings of visible difference and moral judgments about what appearance may say about individual character. These images form part of our collective imaginations about the meaning of visible facial difference and serve as part of our social context.

Twine (2002) historicises discourses of physiognomy, finding indications that judging by appearance is neither timeless nor absolute. But he is not seeking to underestimate embodiment:

"...my particular critique of physiognomy is not about excluding the body from our self-constitution, but about resisting the body's entrapment within physiognomic discourse that tends to define our bodies for us" (Twine, 2002, p.83)

Individuals who live with visible facial differences experience higher social visibility. Their difference can affect interactions with other people as well as feelings about the self (Rumsey and Harcourt 2005; Uttjek et al., 2007; Feragen, 2012). But Twine (2002) questions the value of popular faith in direct representational relationships between a visual appearance and generalised meaning. This line of argument has been taken by others. Garland-Thomson (2011), taking a perspective informed by critical feminist disability theory, contends that shared human experience of embodiment is influenced by a cultural ability/disability system of significance. This affects how we see and live the limits of our bodies, their aesthetics and appearance. She defines the ability/disability system as:

"...a pervasive cultural system that stigmatises certain kinds of bodily variation." (Garland-Thomson, 2011, p.17)

This perspective challenges ideas that differences associated with disability are about inferiority or tragedy. Instead comparison of bodies is seen as embedded in culture and used to interpret an unequal distribution of resources, status, and power within a biased social environment (Garland-Thomson, 2011). This broader view of disability is able to include ideological categories such as

'ugly', 'maimed' and 'mad'. Garland-Thomson's argument is that this ability/disability system serves to privilege categories such as 'beautiful', 'healthy', and 'normal' and it is in the interaction between bodies and the world that disability becomes material above and beyond usual human variation.

Appearance norms have a long history within western culture (Synnott, 1988) and the perspective offered by Garland-Thomson adds that health norms provide similar cultural functions. These cultural ideas, alongside market mechanisms, push bodies towards a set of standards called 'normal' and 'beautiful'. From this perspective, the idea of beauty has become suffused with the idea of normal, producing a tendency at an individual level to avoid associations of 'disabled', 'ugly', 'fat' or 'raced'.

### Encountering facial difference

Two of Goffman's central areas of concern, interaction order and stigma, are key in the sociology of facial difference (Goffman, 1963, 1982 and 1990).

All encounters take place within an 'interaction order' with socially and culturally situated rules of conduct, which all individuals are both subject to and creative of. Within this order Goffman described 'face-work' as a technique and a metaphor for a version of the self which is projected socially. It has ritualised forms which are recognised by others, such that if we get the rules of an encounter wrong it can be mutually embarrassing. Garland-Thomson (2009) reasons that atypical faces throw simple recognition rituals into chaos, the loss of ability to read the social situation heightens the risk of uninvited 'face-work' coming about such as staring, (we examine staring as both useful and destructive later).

Goffman (1963) conceived of stigma as exhibiting both psychological and social processes, it is a condition of the interaction order rather than an objective of it. He identified 'discredited' persons as those whose social status is stigmatised and argued that it is apparent to others who respond to it. There are 'discreditable' person's whose stigmatised social status is not apparent, but who are responded to as if it were. It is significant that Goffman draws from the early work of Macgregor et al., (1953) on facial disfigurement to illustrate his argument.

For Goffman the face is not the property of an individual but something performed or acted in social interaction, it is symbolic. Coupled with his conceptions of stigma, 'face-work' produces ways of interacting that seek to maintain 'face' in encounters and social interaction. Social situations are maintained by strategic cooperation between people using reciprocal face-work to maintain their own face as well as others'. This account has been critiqued and developed to incorporate conceptions of power and discrimination into stigmatisation processes (Link and Phelan, 2001,

2006; Scambler, 2009). Kleinman and Hall-Clifford (2009) suggest that stigma affects 'that which matters most' to people within their social and moral local worlds. That which matters most includes wealth, education, relationships and life chances. The face is central in human interaction, it functions as a means of communication and our face becomes our unique social identifier (Seymour and Lupton, 2004). 'Face-work' produces shared ideas about what faces should look like, and how they should move. What is in danger of being lost by the impact of stigma is the integrity of a person's social self. The practices of 'face-work' acts as a mechanism for coping with bodily stigma (Talley, 2008).

Our eyes are drawn to faces of other people as the face is a key part of our communicating body. Black (2011) uses the idea of a 'multiplex' as a metaphor to understand the fluidity, complexity and lack of fixity that is the face. He argues that multiple accounts of the face (from social, psychological, medical and cultural perspectives) do not fully capture what a face is and what a face does. To see the face only in terms of 'subjectivisation' underplays the anatomical and cognitive uniqueness of the face as a living organ of communication and he argues that it is untenable to regard communication as detachable from bodily materiality. Turning to how the face is used, Black (2011) highlights the cultural specificity of the ways that social interaction occurs; he writes:

"...the face as a material component of the body, which is never fully fixed, grasped or possessed by the viewer of the face."(Black, 2011, p.21)

Socially constituted structures of significance are used to stabilise and fit faces into categories such as 'beautiful', 'ugly' or 'acceptable'. The face is presented as significant in the processes of recognition, communication and in creating relationships between bodies. Black concludes that the lack of fix in these biological and cultural processes leaves room for variation at the level of lived experience. Facial difference can be seen as having the potential to affect a number of complex, multiple, intra- and inter-personal processes involved in the interaction between an individual, the onlooker and society.

Effects of bodily difference cannot be set aside in processes of interaction, having a body which is different affects perceptions and behaviour both of the person with the difference and of others. While visible facial difference may not (using a narrow definition of disability) disable, a loss of confidence connected to appearance can prevent people doing what others take for granted. People may need to negotiate difference in everyday life and being visibly different to others is important for both self-identity and inclusion.

A particular example of face work and of the operation of stigma is provided by Garland-Thompson. In 'Staring: How We Look' (Garland-Thompson, 2009) she draws on Langer who hypothesised that people stare at "novel stimuli" as a form of "exploratory behaviour" (Langer et al., 1976, p. 461), as a means of reducing unease and uncertainty in an uncertain world. There is automaticity in staring:

"Stareable sights seduce us into an attention crisis in which random visual intrusions, not a disciplined will, assert control" (Garland-Thomson, 2009, p.21)

Staring has useful as well as destructive powers; it is a form of communication as well as an expression of dominance and stigma assignment. What Garland-Thomson argues is needed is a wedge between acts of staring and negative judgements. She proposes an ethics of looking and of being looked at, and suggests that we consider how we should stare rather than whether we should stare.

"We become ethical starers by being conscious in the presence of something that compels our intense attention. What gives such attractions power in these formulations is their capacity to vivify human empathy through bearing actual witness.....the impulse to stare at novel sights , whether we understand them as conventionally beautiful or repulsive, can move us toward recognising a "newness" that can be transformative. These stareable sights disturb not just the visual status quo but the ethical status quo as well" (Garland-Thomson, 2009, p.188).

Face work and the operation of stigma, including staring and the experience of being stared at, are situated within personal lives and social worlds.

### **Personal lives and social worlds**

Early work (Macgregor et al., 1953) positioned 'facial deformity' as a source of psycho-social difficulty. It was argued that there was a potential for exclusion because of challenges in finding employment or marriage partners. The family was regarded as a haven in a hostile world. The social world is much changed since the 1950's not least through the impact of civil rights, feminist, and disabilities movements as well as questions about whether families are still sources of social cohesion in an individualised, post- modern, post-industrial, consumerist, networked global world (Giddens, 1992; Plummer, 2001; Bauman, 2003 and 2004; Spencer and Pahl, 2006).

Macgregor et al., (1953) began exploring facial disfigurement in plastic and reconstructive surgery clinics at the end of the Second World War. She identified that having an atypical face was potentially a significant social problem for the person affected, as the face was central to the person and their social relations and interactions. She found the main difficulty associated with facial disfigurement as being a psycho-social threat to mental health. Some people living with

disfigurement found establishing relationships problematic and were hampered by beliefs that they could not be loved because of their appearance. Her interviewees spoke of experiences of rejection and as feeling unsuitable for marriage or their desired employment. Her studies explored families with children who were disfigured from time of birth or during childhood, its impact on the family and specifically on maternal attachment. Adult family relationships were not explored in depth, although 'success' in achieving friendships and marriage was recorded. Interviews were interpreted as indicating that some people had perceptions of having constrained relationship choices and of having married "beneath their class".

Since Macgregor's work feminist scholarship have challenged the idea of family as simply supportive by revealing gendered inequalities and the role of the family in perpetuating these (Gillies, 2003; Jamieson, 1998). There has been an increase of divorce, and lower levels of marriage as well as more single parents and greater numbers of step-families. These changes have been used to illustrate significant transformations in personal relationships as developed under the various forms of the 'individualisation' hypothesis (Giddens, 1992; Bauman, 2003). This hypothesis characterises society as becoming more atomised and individuated. There is an increasing lack of commitment to others and an increase in isolation for some. Shakespeare (2006) expresses concerns that people living with disability may be disproportionately affected by social changes that increase isolation and disconnection. As well as social connection, relationship with others can be seen as constituting the self as a social self (Burkitt, 2008; Ketokivi, 2012). Burkitt (2008 and 2012) extends conceptions of the social self by taking a dialogic perspective. This takes a thin view of the individual with a thick social relational view to the self (Smith and Sparkes, 2008). He addresses how sociocultural conceptions of subjectivity are able to incorporate damaging and conflictual aspects of how humans are with each other and themselves.

The complex and textured personal worlds of people living with facial difference reveal narratives of resisting, developing, and adjusting to living with being visibly different to people who surround them. Through narration of linkages and connections, stories of embodied emotional bonds emerge within a wider web of relationships and with a sense of social location (Smart, 2007; Plummer, 2001). Experiences which are personal also have social significance; they speak of acceptance, love, reciprocity and living across difference. They also tell of rejection and loneliness (Smart, 2007; Shakespeare, 2006). Shakespeare (2006) identified isolation and loneliness at particular points in the life course for people with disabilities that is neither easily overcome by barrier removal nor explained by oppression alone. There are, he argues, well documented difficulties of interaction, reciprocity and respect between non-disabled and disabled people.

Social networks and personal relationships enmesh our cultural, emotional, psychological and social well-being (Phillipson et al., 2004). We become who we are through our contacts with others, our friends, companions and families. Benefits are found from support and participation in social networks in areas of health (Gallant, 2003), ageing (Allen, Blieszner and Roberto, 2000) wellbeing and living with chronic health problems (Vassilev et al., 2010). Individuals' networks are also doorways to resources in the wider social world of work and education. Networks deliver more than support, having relational and affective dimensions of love, friendship, companionship, intimacy and generation of purpose (Smart, 2007; Gabb, 2008; Mason and Davies, 2011; McCann & Roberto, 2012). In a study of friendship Spencer and Pahl (2006) used the concept of personal communities to extend understanding of how people in postmodern times value a range of social ties.

Characteristically, relationships with families and friends overlap and inter-relate in their functions. They explored degrees of connectedness and belonging, commitment to others and patterns of reliance on 'given' and 'chosen' ties. No single 'normal' pattern dominated.

Spencer and Pahl (2006) explored the meanings of relationships within social networks and asked what connections 'do' in individual lives. Their study contributes to a growing number of empirical studies which challenge an 'individualisation' thesis (Jamieson, 1998 and 2011; Smart, 2007). They suggest that friend and friend-like relationships from families act as 'social glue' and provide a range of social connections. In some people's lives friends were more important than family and they argue that the role of personal relationships is under recognised as a form of 'social capital' that has both health and social benefits.

Spencer and Pahl (2006) investigated individual's communities to capture patterns and functions associated with active and intimate ties. These are seen as 'communities in the mind', representations of people's networks across different types of relationships, places and time. It is an approach that differs from a focus on place-based or family-based groupings (Pahl and Spencer, 2004). By looking back over the life course, shared histories, times of adaptation and times of continuity can be seen. This has been described as a 'social convoy' and it includes people known at earlier times even if the contact has not been maintained (Antonucci and Akiyama, 1987). A number of studies have explored subjective perspectives on personal social networks in self-care and management of long term conditions (Vassilev et al., 2011; Morris, 2011), identity (Ketokivi, 2010, 2012) and ageing (Kahn and Antonucci, 1980; Antonucci and Akiyama 1987; Wenger 1990 and 1997). Wellman and Wortley (1989) found that no single type of relationship provided support, rather it flowed through informal networks, people found different types of support from different people. Ketokivi (2010 and 2012) investigated social selves and found both individuality and social bonds

emerged from relational networks. She argued that this is at odds with the societal expectation of an autonomous individuality and that this becomes more apparent when people are dealing with change.

### Visible facial difference

*Changing Faces*, a charity prominent in championing the rights of people living with facial differences, describe disfigurement as “the aesthetic effects on facial appearance of a scar, mark, rash, or a skin graft on a person’s facial skin or an asymmetry or paralysis to their face” (*Changing Faces*, 2009, p.1). These can be manifest at birth or develop or occur at any time of life. Appearance cannot be measured objectively and there is no specified range for normal appearance (Harris, 1997). Expectations of how we ‘should’ look affect how we see ourselves and others, and they affect our ideas about what is normal or different about our appearance as detailed above. Facial differences have an embodied and emotional social reality without their being a clear cut objective definition (Talley, 2008).

OPCS’S Disability Survey (Martin et al 1988) estimated there were at least 400,000 people in the U.K. with a disfigurement to their face and/or body defined as a scar, blemish or deformity which severely affected their ability to lead a normal life. This survey did not distinguish location of disfigurement and combined face with any other part of the body. Furthermore the focus of the survey was to identify impairments which interfere substantially with activities of daily living (Abberley, 1992). Many people living with visible facial difference do not have continuing illness conditions or necessarily have conditions that affect activities of everyday life but may find themselves with difficulties in particular situations or types of relationships in their social and personal worlds. Consequently, the OPCS survey is thought to underestimate the number of people who live with a facial disfigurement by not including those whose lives are affected by the social or psychological consequences of difference (Newell and Marks, 2000; *Changing Faces*, 2007).

*Changing Faces* have estimated that 542,250 people in the U.K. have a significant disfigurement to the face (*Changing Faces*, 2007). This estimate uses a broader definition than the Disability Survey (Martin et al., 1988) and focussed on the face and head only. The *Changing Faces* estimate also differentiated disfiguring conditions by extent and by location on the face. They included: congenital conditions; accidental causes such as burns, scarring and facial fractures; cancer treatment and disease process; eye conditions such as loss of eye; facial paralysis and skin conditions such as psoriasis, vitiligo and acne. Facial difference does not just affect visual aesthetics; also implicated can be other facial processes and sensations such as smiling, facial movements, vision, speech, hearing and texture of the skin. The multiple categorisations of facial disfigurement complicate

estimation of prevalence of disfigurement and no epidemiological studies appear to have been carried out which untangle this area. The subjective aspects of visible facial difference further complicate the ability to produce a judgement of when an appearance can be said to be altered or disfigured. Recent work from within the field of appearance psychology indicates that the subjective judgement by the person affected is better able to account for degree of distress (Moss, 2005).

There are a number of books written by people living with acquired facial difference in the UK.; Christine Piff (1986), Simon Weston (1989 and 2003), James Partridge (1990), Katie Piper (2011) are prominent. These accounts discuss challenges of resisting, adjusting, and achieving in the face of difference. The story of facial difference experienced since birth is different and one less frequently told as identified by Zitzelsberger (2005).

### **Living with visible facial difference: disruptions, continuities and normalities**

A significant change in facial appearance can be a disruptive life event breaking biographical expectations in an acute way. It may require a re-working of relations with significant others, as well as a shift in self-identity (Bury, 1982). For people who have lived with a disability or condition for all or much of their life Williams puts forward the idea of biographical continuity instead, with self-identities (both physically and emotionally defined) being generated reflexively through a cyclical process of “biographical revisions” across the life course (Williams, 2000, p.57). As a group, people living with visible facial difference do not necessarily share life experiences or the same causative experience or condition even though they may share similar experiences of being stared at or experiences of discrimination (Clarke, 1999). The diversity of biographies and causes of visible facial difference, work against there being any essential identity of visible facial difference, or of there being a single pattern of responses or of personal communities.

The following vignettes provide a glimpse of how the multi-dimensional nature of personal communities and the phenomena of living with visible facial difference come together and are mediated or hindered through a cosmopolitan gaze. The vignettes also illustrate a difference between respondents in the extent to which they experienced past or present personal communities as supportive. They have been drawn from interview accounts, pseudonyms have been used and personal detail in the extracts changed or anonymised. Respondents were recruited via advertisements placed on the websites of charities and support groups concerned with issues of visible facial difference. Respondents volunteered for the study and were living with a range of visible difference from birth or acquired later in life. Interviews were carried out between September 2011 - August 2012.

### **Vignette 1: Incorporating visible facial difference**

'Isobel' talked about how her personal community was strongly embedded within a large family network. In this quote she illustrates how other people outside this network can get confused about what her appearance might mean about her.

*So yes, I think it's being seen as being normal. That's what it always meant to me doing sort of normal activities and not sitting in a corner, but going out and getting on with your life, because you have to have a life at the end of the day.*

Interviewer: When you use the word normal what does that really mean?

*I don't know (laughs) what other non-disfigured people do or what I presume they would be doing. Do you know what I mean?*

Interviewer: This is an embarrassing question, but do you think that at some level being disfigured makes you abnormal?

*No it doesn't, no it doesn't does it, no, (laughs) no to some people it probably makes you abnormal, people think you have special needs and that, you know, educationally, do you know what I mean, but which is really bad that someone should think that because you have got a disfigurement that you are mentally handicapped. But then this view of mentally handicapped people, as well, is completely out of order. But I suppose it's doing what non-disfigured people do. And it's being part of that world as well, and the fact that I don't know, it's just being a part of everything I suppose. I mean there are a lot of people with disfigurement but, do you know what I mean, you are not going to be socialising with them all of the time and, do you know what I mean? I think it is important that you are out in the world.*

In her everyday world 'Isobel' challenges assumptions that she is defined by her facial scars through her interactions and activities in her family, personal, and professional worlds. 'Isobel' has lived with visible facial difference from birth and had corrective surgery during her childhood. In her interviews she indicates ways in which she is ready to challenge assumptions at a more public level. She has joined a user council of a charity and is contributing to their development of resources.

### **Vignette 2: Finding unease in everyday life from the unpredictability of others**

'Eve' has a job she loves. She finds the professional environment she has chosen to work in reduces the possibility of untoward comments and stares, enabling her to feel at ease and to get on with her role. A sense of unease can develop when she has to go to new environments as described in the quote below:

*And then meeting people like, part of my job is I go out to other businesses and try and sell [the] products and services that we can offer. Sometimes that can be quite daunting as well because you never know how people are going to react. Not that they ever say anything, but you can see the looks and just little things that you get used to and pick up on really. So it's quite hard. Inside my friends and family I don't think about it but then outside it can become quite uncomfortable*

Interviewer: So what's the difference then?

*I think it's because with my friends and family I know they have accepted me and I know are not judging and I know they are not thinking, 'oh she is different'.*

She has built up a pragmatic working knowledge of others, from a life time of encounters with people who have different conceptions of normal behaviour; Eve was born with a visible facial difference. She underlines that the processes involved are emotional and embodied, and contrasts being out in the world with her safer work environments. Her personal community of friends and family members provide a social space where unease can disappear.

### **Vignette 3: Contributions of friends and family**

'Ken' talks about the processes of getting used to 'disturbances' other people experience in response to his facial appearance. He, his family and friends have had to learn how to deal with this in everyday life, after an accident in his childhood that left his face scarred. He calls this 'normalisation', and sees this as a process of developing a life that is not defined by his visible facial difference. For him part of this process included having to learn to recognise his own changed face, later he learned that other people also needed to go through a similar process. These processes of learning how to live with change gave him an understanding of the intersubjectivity involved and a more flexible range of strategies he could draw on, including building up social connection and support. The significance of change over time can be seen.

*.... you know that what people are seeing is the image that you have got in here now, and then you build relationships and friendships around the fact that it's not that important, and the importance of the scarring and disfigurement goes down and down and down.*

*And I would say to you now that the people that I have around as friends, family and all the rest of it, it's my visible difference is down here somewhere compared to 20 or 30 years ago. I was first of all aware that I was going to walk into a room and someone was going to stare at me.*

*There are people who [say], I don't know how you put up with it. Put up with what? You know all those people? What people? I don't see them; I didn't see the people who stare. Sometimes I do and sometimes when I am not in the right mood, I get cross and I've got blinkers on I can remember developing those blinkers, but so you normalise everything.*

*The friendships the relationships you are going to see are first and foremost about people who are, there are things about my family, obviously, they'll have to deal with the, people who stare, people who look, but they have done the same kind of things, the switching it doesn't bother them anymore.*

#### **Vignette 4: When illness has not stabilised**

Building up a supportive network takes time and is contingent on one's own preferences as well as others capability and resources. 'Tom' talked about how his social relationships have changed since his surgery in response to head and neck cancer.

*My illness has literally stopped my social life. It just went.*

Interviewer: Is that because you stopped organising things?

*We were the ring leaders and we stopped.*

Interviewer: Do you think whether social life is important when you are unwell?

*Yes, I think it depends on how ill you are. I have been ill and I am ill, but I can function. I still need to function and get my head on my shoulders and not lock myself in the house and not go anywhere... So I think if you don't, I think we can get into a little corner and you wouldn't see anybody then. You might get the odd call but people just assume 'Oh he doesn't do it anymore and doesn't get involved with anything' and people just leave you alone and you would lose contact with the real world really. I think if you can manage to get out and about and do things, or have people around, or just have some sort of life outside of the couple because you need other conversation. I mean you have to have other people apart from the two of you. I think you'll cease to function as a person I mean, and I feel like that at times.*

This extract reveals some of the difficulties faced when confronting a dramatic change of bodily function, facial appearance and social circumstance, which can accompany a biographical disruption (Bury, 1982).

Overall, the vignettes provide examples of individual agency on the part of people with facial difference. We have explored the impact of the way bodies are represented in society and of the prevalence and impact of appearance norms. We have considered interaction order and stigma and the active engagement of the person in seeking networks of support, many of them from within their family. But in these examples, although we do hear of the challenges of encountering the often unspoken reaction of others in the public sphere and the temptation to retreat to a safe zone of the familiar, we also hear of the sense of acceptance and of normality that can be achieved through the individual's actions, supported by those closest to them.

## Conclusions

People with a visible facial difference develop personal communities shaped by their life stories. Social experiences are embodied but mediated by the subjectivities of the self and the 'gaze' of the other. Networks and relationships offer positive experiences and meaning making that co-exist alongside negative aspects of disability and injury. A complex reconciliation of tensions is possible over the life-course, evident as a continuous process of adaptation rather than a process with a fixed end point. As Ungar puts it:

"The successful individual or family is the one that functions to a standard he, or she, or it sets in concert with others whose opinions are valued. In such a negotiated realm, individual families (and family members) will be looking to elicit from complex environments meaningful resources. The most resilient will have the most responsive physical and social ecologies" (Ungar, 2010, p.13)

Professionals are most likely to be helpful when they share with their clients the skills to help cope with change and complexity, focussing not on outcomes but on processes.

We indicated how living with visible facial difference raised particular challenges for the limits of cultural cosmopolitanism. The literature we have referred to, and the examples from the study we report, underline a continuing tension in achieving the openness to the other that cosmopolitanism requires. The tension in cosmopolitanism has been identified as one between hospitality to strangers and a fear of the other (Skrbis and Woodward 2005). This is resolved in many instances by a limited openness, shaped by an aesthetic of inclusion: we embrace and incorporate those who add to our particular formation of cosmopolitanism. In a visual culture this means that we take few risks in extending hospitality to others who we find uncomfortable to our aesthetic. In Jonathan Glazer's film "Under the Skin" (Studiocanal, 2013) an alien with no compunction about murdering the humans she encounters meets one with a profound facial difference. She engages with him in a way that those in his own "society" do not, seeming to not notice his face and complementing him on his "beautiful hands". Our skills do not equip us to look beyond some manifestations of embodiment.

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