

# 5-year Strategic Plan, 2009-2014

## Background

In the autumn and winter of 2008-09, *Changing Faces* conducted an important review of its progress over the last 3 years. This was the first full-scale review since 2006 when it adopted its revised strategy of being a charity acting as a Catalyst for Change and as a campaigner for face equality in society (see Annex 1 for more on that decision).

This year's review coincided with three important developments:

- the sharp and deep recession that is now gripping the global economy
- the achievement of major new funding commitments notably for our Catalyst Programme
- significant new pledges and gifts towards the final repayments of the £1m loan on our HQ, the Squire Centre: there is now 'only' £175,000 to raise by July 2009
- the (pro bono) analysis and presentation of our international options from Deloitte's Global Strategy team.

## Executive Summary of our 5-year Strategy

*Changing Faces'* long-term and ambitious mission is to create a better and fairer future for the 1.3m people in the UK and the many others worldwide who have facial and other disfigurements, whether from congenital conditions, accidents, burns, cancer surgery, skin problems, facial paralysis or other cause.

This 5-year Strategic Plan describes our vision for taking the charity forward from its present £1.2m scale with a 25 wte staff team. Over the next 5 years, we aim to build on the charity's exciting track record and its sound financial foundations by continuing to expand our activities in the UK and, as resources allow, by gradually developing a growing international presence. All our work will be driven by three aims:

- to be the best-practice source of psycho-social support and empowerment for individuals with disfiguring conditions and their families
- to act as a vigorous Catalyst for Change in transforming health care services, education curricula and employment policies that people with disfigurements experience
- to campaign for face equality so that people with disfigurements are socially included, leading full lives, free of prejudice and discrimination in the UK and other countries.

The timing of how the charity develops will depend on the resources available, how sharp are the recession's effects and our own careful judgement of the capacity of the charity to grow.

Our Annual Plan for 2009-10, the first year covered by this Strategic Plan is summarised in Annex 2 and our current staffing structure in Annex 3. Both the Plans should be read in conjunction with other literature (eg: our Annual Review, our accounts, the booklet *Facing Changes*, and our leaflet).

*More details can be obtained by contacting James Partridge, Chief Executive, via his Executive PA, Claire Marley, on 020 7391 9272 or [clairem@changingfaces.org.uk](mailto:clairem@changingfaces.org.uk)*

## 1. Our raison d'être, mission, vision and aims

*Changing Faces'* mission is to create a better and fairer future for the 1.3m people in the UK and the many others worldwide who have facial and other disfigurements from any cause.

Our goal is a fair and just world where...

- everyone with a disfigurement has full human rights to respect, fairness, and access to effective psycho-social help/services to strengthen their self-esteem and self-confidence
- all professionals and every health clinic, school and workplace are informed and skilled to tackle the psycho-social effects of disfigurement confidently
- everyone in society (whether or not they have a disfiguring condition) respects face equality and can face disfigurement with confidence, free of prejudice and discrimination.

The scale of the need is considerable: disfigurement is much more widespread than is commonly realised; public attitudes are unconsciously negative; the subject is shrouded in fear, taboo and stigma.

540,000 children, young people and adults in the UK have a significant facial disfigurement – one person in every 111 people. Up to 1.3m people have body disfigurement (one in 45 people). See Annex 4 for more epidemiological details. Medical and surgical treatments for these conditions are increasingly sophisticated but they can rarely remove a disfigurement.

Our raison d'être is that the charity exists because...

- individuals with disfigurements are far too often alone, feeling socially and economically excluded, with low self-esteem and confidence, lacking support and empowerment
- the vast majority of the UK and other countries' health/social care, educational and employment services are inadequate in addressing people's psycho-social needs
- in our looks-obsessed world, disfigurement is viewed uncertainly and negatively with the result that people with disfigurements too often encounter unconscious facial prejudice and discrimination which can diminish their life chances.

*Changing Faces* exists in order to...

- support, advise and inspire individuals with disfigurements of all ages and their families
- help to develop and advocate for improved health/social care, education and employment
- transform public and institutional attitudes and behaviours to respect face equality so that people with disfigurements are accorded fairness, informed acceptance and inclusion.

We aim to support and represent the interests of people with disfigurements in the UK and, as resources allow, in other countries by:

- CARING: innovating/providing psycho-social help for individuals and families (eg: counselling, social skills training, workshops, school support, self-help information)
- ACTING AS A CATALYST: promoting professional awareness, skills and best practice in health care, education and work to meet people with disfigurements' psycho-social needs
- CAMPAIGNING: promoting public awareness and campaigning for equal rights and opportunities for people with disfigurements.

## 2. Why is *Changing Faces* unique: our history and qualities

*Changing Faces* was created in May 1992 by its now Chief Executive, James Partridge OBE. At the outset, the primary goal was to pioneer and provide a new package of psycho-social help for people with facial disfigurements (especially emphasising social skills training); secondary goals included mainstreaming this help to complement medicine and surgery and changing public attitudes to disfigurement.

A brief overview of our history:

- **April 1990:** James Partridge's Penguin book published reflecting on the lessons learned after he was severely burned in a car accident (1970); in May 1990, he met academic, Nichola Rumsey (now VTCT Professor of Appearance Psychology, University of the West of England) which led to the first social skills workshops in the autumn of 1991
- **May 1992:** *Changing Faces* registered as a Charity, No 1011222, and launched at the King's Fund Centre, London
- **1992-95,** based at 27 Cowper St, London EC2; income £125k - £300k pa, up to 3 staff. Key achievements: developed workshops and counselling for adults with disfigurements, with research proving their value in raising self-esteem and confidence; successfully campaigned for disfigurement to be covered by the Disability Discrimination Act 1995.
- **1996-2004:** moved to 1-2 Junction Mews, London W2, income £350k - £700k pa, expanding to 15 staff. Key achievements: developed children and young people's service, schools support and self-help guides; launched the first poster campaign about disfigurement throughout the UK; created the first Disfigurement Support Unit at Frenchay Hospital in Bristol, now an NHS service; partnered the University of the West of England to create the world's only Centre for Appearance Research
- **July 2004:** acquired 105-year lease on 33-37 University Street, London WC1, which was completely refurbished by November, renamed The Squire Centre and formally opened by one of our Patrons, the Duke of Westminster, on 3rd December 2004
- **2005-2009:** Squire Centre, £750k - £1.2m, now 25 wte staff. Key achievements: Strategic Plan 2006-09 announces shift of the charity's emphasis to being a Catalyst for Change and a campaigning force; *Changing Faces* Officers established in Wales, Scotland and Northern Ireland during 2006 and 2007; created a Young People's Council and associated young people's website ([www.iface.org.uk](http://www.iface.org.uk)); launched the Face Equality campaign in May 2008 which is already supported by hundreds of people and 12 major employers; presently expanding our team of Advisors with 5-year funding of £200,000 pa from the Vocational Training Charitable Trust.

*Changing Faces'* unique qualities are:

- Personal Insight and Objective Expertise: *Changing Faces'* greatest strength and quality is the unique marriage of the insights gained from the lived experience of facial disfigurement and the knowledge gained from academic and research-based sources. This makes *Changing Faces* unique and a world-leader in facial disfigurement.
- Human touch: *Changing Faces* works very closely with individuals and families and in doing so makes a radical, life-changing difference to people dealing with a disfiguring condition. This ethos permeates the organisation: for all its advocacy and campaigning, it is fundamentally about reaching people in need, being a friend and empowering them.
- Fairness: Fundamental to *Changing Faces* is the pursuit of fairness: we believe that fairness means that people with disfigurements should be accepted for who they are, not judged by uninformed prejudices about their facial features. We are determined to rectify the injustices that are caused by fear and lack of understanding of disfigurement.
- Pioneering: The charity has a strong pioneering record which is – and will continue to be – reflected in an indomitable can-do, 'anything's possible' mentality to all events.
- Campaigning: *Changing Faces* is committed passionately, energetically and uncompromisingly to promote face equality in all aspects of life in the UK and globally.
- Inspiring and Challenging: *Changing Faces* is always constructive about the challenges of disfigurement (not hectoring or angry); it never 'tragedises' those with disfigurement in any way. Instead, it understands why many find disfigurement hard to deal with and is 'a critical friend' to those who wish to change, engaging and inspiring them, leading with charisma and by example. However, it is also not afraid in pursuit of its mission, to challenge existing prejudices and assert the rights of people with disfigurements.

## Our Programmes as at April 2009

Our Programmes are inter-related and informed by our Young People's Council and other users. Our work is underpinned by academic research evidence and by ongoing evaluation.

Each Programme has a specialist team and is run by one or two Heads who are also active on the ground.

### ▪ **Individuals Programme**

People with disfigurements can and do live full, valuable and happy lives but many need specialised psycho-social help to be able to face people with confidence and make the most of their lives.

*Changing Faces* specialises in working with children, young people and adults with disfigurements, and those close to them, to strengthen their self-esteem and confidence by gaining 'disfigurement life-skills'.

The Programme has two parts – our Children and Young People's Service and our Adult Service. Each employs Specialists who provide and test new ways to help through one-to-one counselling, workshops and family days, self-help guides, an interactive website for young people, and school-based support for children.

### ▪ **Professionals Programme**

Surgical and medical treatments for disfiguring conditions are very important: they are often life-saving and can be aesthetically beneficial but they can rarely remove a disfigurement completely. Patients and families need to have access in their locality (ie: hospital, GP) to disfigurement-specific psycho-social help to build self-esteem and confidence. As pupils, employees and customers, they need access to disfigurement-confident support to manage the everyday social challenges when attitudes and behaviours have a significant impact.

Our 10-strong Professionals team provides expert advice and specialised training and works to influence policy on the delivery of local/national services, working with professional associations and representative bodies.

During 2009-10, our UK Network team of half-time Officers in Wales, Scotland and Northern Ireland which are an integral part of the Professionals Programme will be expanded and be created as a 'Programme' in itself. The plan is to recruit a new Head of the UK Network to develop this project with Officers in 5 English Regions – the North, the Midlands, the South and South West, the East and South East, and London – as well as in the devolved countries; a full team should be in place by March 2010.

### ▪ **Society Programme**

Everyone irrespective of their appearance has the right to be, and be seen to be, respected and included in society for who they are; no-one should be discriminated against or disadvantaged because of their disfigurement or appearance.

*Changing Faces* is committed to raising awareness of the issues faced by people with disfigurements and to advocating for a society which fully respects face equality.

Our 3-strong Campaigns and Communications team aims to transform public attitudes and behaviour about disfigurement via the media, PR/external relations, informative literature and our website. It is the prime driver of our face equality campaign.

Underpinning the Programmes, we have a **Research Fund**, an **Operational Support** team of three people, and a small **Fund-raising** team headed by the CEO.

### 3. Our vision for developing the charity over the next 5 years

At the beginning of April 2009, the vision for *Changing Faces*' development over the next 5 years is that the charity should grow its activities and campaigns not just in the UK but internationally too. Such an international programme will require significant funding and a strategy of gradual development.

The timing of this growth is dependent on whether and when that funding can be secured and on the charity's capacity to manage the change and growth. The gloomy global economic outlook is likely to make the search for funding more difficult but not impossible.

We have therefore described what we think could be achievable in this coming year and what we would like to achieve by 2014. The speed of development towards those long-term goals is impossible to define precisely at this time.

In the short-term, in 2009-10, we are determined to continue to develop all our activities and campaigns – and with due caution and close attention to cost control and by stepping up our fund-raising efforts (see Annex 2 for the Executive Summary of our Annual Plan 2009-10). That Plan includes expanding our UK Network team with a new Head and eventually 5 English Regional Officers, and launching the Face Equality campaign into the media, schools and the NHS. We will not take our eye off the UK in a way that might jeopardise our efforts.

We envisage the steps to our desired growth could be:

#### April – September 2009:

- Complete and celebrate the repayment of the £1m loan – a further £175,000 is required
- Gain the use of (tenants leaving 31.3.09) and, once funds are available, fully refurbish the 'West Wing' of the Squire Centre so that the staff team can use the whole property
- Consider and decide how the charity's governance, leadership and management, including its fund-raising efforts can best be evolved
- Explore options for seedcorn funding and for the funding of the six possible strands of a future International Programme as described by the Deloitte's Global Strategy team (October 2008):
 

a. Online publishing	d. Centre of Excellence
b. Franchise	e. NGO partnership
c. Education	f. In-country effort
- Decide which strands should be pursued if funding can be found.

#### October 2009 – March 2010:

- Instigate the search for the seedcorn and other funding needed to develop an international presence for *Changing Faces*
- Develop the new arrangements for the charity's governance, leadership and management, recruiting and inducting as required

Looking further ahead, our vision is that by 2014, *Changing Faces* will be recognised as:

- being the world's leading source of psycho-social help and inspiration for people with disfigurements and their families, including in many languages and online
- having the capacity and competencies to provide expert advice for professionals and policy-makers throughout the world in health, education and the workplace about how to address the psycho-social needs of their patients, students, employees and customers with disfigurements
- being highly influential in promoting face equality and inclusion in all cultures across the globe where attitudes towards disfigurement are predominantly negative

We intend to devise appropriate ways to assess whether or not we have achieved these aspirations and to report on them annually.

#### 4. The outcomes we aim to achieve

Looking at the outcomes of our efforts over the next five years, we aspire to make the following happen, towards our long-term vision (*in bold italics*) of a fair and just world. Indicators and baseline figures to measure these improvements will be introduced.

Please note that these outcomes are entirely UK-focused at this time but will be complemented by international goals as our International Programme is put into action.

***Everyone with a disfigurement will have full access to effective psycho-social help to strengthen their self-esteem and self-confidence***

By 2014:

- The numbers of people contacting *Changing Faces* for direct help will have increased by 10% per year – including the hits on the clients' sections of the websites
- The number of parents down-loading or acquiring our 'top tips' to support their child in adopting positive attitudes and building self-confidence will have increased by 10% pa
- We will have disseminated 20,000 copies of our new self-help guide for adults with disfigurements and parents/families.

***Every health clinic, school and workplace will be informed and skilled to tackle the psycho-social effects of disfigurement confidently***

By 2014:

- The NHS standards and guidelines for the treatments of five of the major disfiguring conditions (eg: clefts, burns, head and neck cancer, skin conditions and facial paralysis) will recognise that psychological care should be integrated routinely into services for patients and families
- The need to provide psycho-social support at GP surgeries for individuals and their families with disfiguring conditions will be recognised in prevailing primary care standards
- Modules on the psycho-social issues of disfigurement will feature strongly in education institutions' under- and post-graduate curricula for medics, nurses and teachers
- National best-practice recruitment policy will recognise the need to respect face equality principles; accordingly, major employers in the public and private sectors will promote face equality through appropriate cultures, attitudes, policies and practices.

***Everyone with a disfigurement will be entitled to and enjoy respect and fairness – and everyone in society will be able to face disfigurement with confidence whether or not they have a disfiguring condition.***

By 2014:

- Face equality will be recognised as a key equality issue by Government and by the Equality and Human Rights Commission and disfigurement properly enshrined in equality and human rights legislation
- There will be a greater diversity of faces in mainstream TV programmes and advertising
- The issue of public attitudes towards disfigurement will be much more widely debated
- A public attitude survey in 2011 will show an improvement in people's attitudes towards people who have disfigurements.

In addition, the aspirations stated on the previous page for *Changing Faces* as an organisation will have been realised.

## ANNEXES

1. The rationale for being a Catalyst for Change and a campaigning charity
2. Annual Plan 2009-10, Executive Summary
3. Organisational structure, March 2009
4. The incidence and prevalence of disfigurement

### ANNEX 1: The rationale for being a Catalyst for Change and a campaigning charity

Since its inception in 1992, *Changing Faces* has been successful in inspiring many people, promoting professional services and influencing public opinion, often far beyond what might be expected of a small charity. However, this success brought with it a problem: as the charity became better known, we faced rising demand for our support from individuals with disfigurements and their families from all over the world, which put pressure on us to expand our counselling staff more and more. Was this what *Changing Faces* should be doing?

In a thorough strategic review in the autumn of 2005, we decided that it was neither sustainable nor desirable for *Changing Faces* to be, or be thought to be, the main provider of psycho-social services for people with disfigurements. Our client service was a model of best practice but we need to enable others, especially professionals, to offer what we offer. Furthermore, many people who contact us want to gain support in their locality from health and education services, that is similar to those provided by *Changing Faces*.

Simultaneously, we also realised that *Changing Faces* is increasingly seen as the national voice on disfigurement issues and is starting to transform public attitudes nationwide (eg: via our advertising campaign). Our supporters tell us that they want us to do this much more.

**We therefore decided that over the next 5-10 years, *Changing Faces* should strategically shift its efforts to empower professionals and influence public attitudes whilst continuing to help, and to innovate new ways of helping, individuals living with disfigurements, and their families, who contact the charity.** So the balance of our efforts would change, with much more effort being put into our work to inform/train professionals, advocate for better services and inform/educate the wider public.

In April 2006, the Trustees decided to focus our future strategy explicitly on what *Changing Faces* has proved it can do very well: acting as a "Catalyst for Change". As the UK's leading disfigurement charity, we would be a Catalyst for Change to bring about improvements in the lives and prospects of people with disfigurements. We would aim to stimulate individuals, families, professionals and the public to transform the way everyone faces disfigurement.

Our ultimate goal was that disfigurement would no longer be a cause of disadvantage – instead, individuals would come to see it as an opportunity for personal growth, professionals would design empowering and effective services and curricula, and society would embrace it as a stimulus for social inclusion – never a reason for stigma, low expectations and discrimination. We have made some good progress towards this goal during the last 2 years and remain totally committed to this strategy.

This Strategic Plan asserts that in 2008-11 we will step up all our Catalyst for Change activities and in our public awareness efforts we will present disfigurement as a major social justice issue. Under the banner of 'face equality', we will create a campaign with powerful calls to action to all sections of the community so that face equality for people with disfigurements becomes a reality. *Changing Faces* will become a more campaigning organisation as a result and will embed 'face equality' principles into all our programmes.

## ANNEX 2: Annual Plan 2009-10, Executive Summary

During the autumn-winter of 2008-09, *Changing Faces* reviewed all its Programmes in light of the progress made in the year and external opportunities and threats including the economic downturn. We are determined to continue to develop all our activities and campaigns – and with due caution and close attention to cost control and by stepping up our fund-raising efforts.

The full Annual Plan for 2009-10 which contains the detailed plans for all our Programmes is available on request. Our current staffing structure is described in Annex 1.

The headlines for 2009-10 for each Programme:

### Individuals and families

- Maintain and develop our existing one-to-one, group and online activities, providing help to the 500+ people and families who contact us for the first time and all ongoing clients
- Nurture the Young People's Council and explore how to increase adult user involvement.

### Professionals

- Grow all our Catalyst for Change efforts in the NHS, schools and with employers, boosted by new VTCT-funded Advisory staff
- Launch the Face Equality campaign into education/schools and the NHS and roll it out further with employers including with a Face Equality at Work membership scheme.

### UK Network

- Recruit a new Head to develop this project with Officers in 5 English Regions as well as Wales, Scotland and Northern Ireland; a full team should be in place by March 2010

### Society

- Galvanise the Face Equality campaign to the public, the media and opinion-formers through eye-catching, attitude-shifting events and partnerships
- Continue to push for informed and positive portrayals of people with disfigurements throughout the media

### Fund-raising and Operational Support

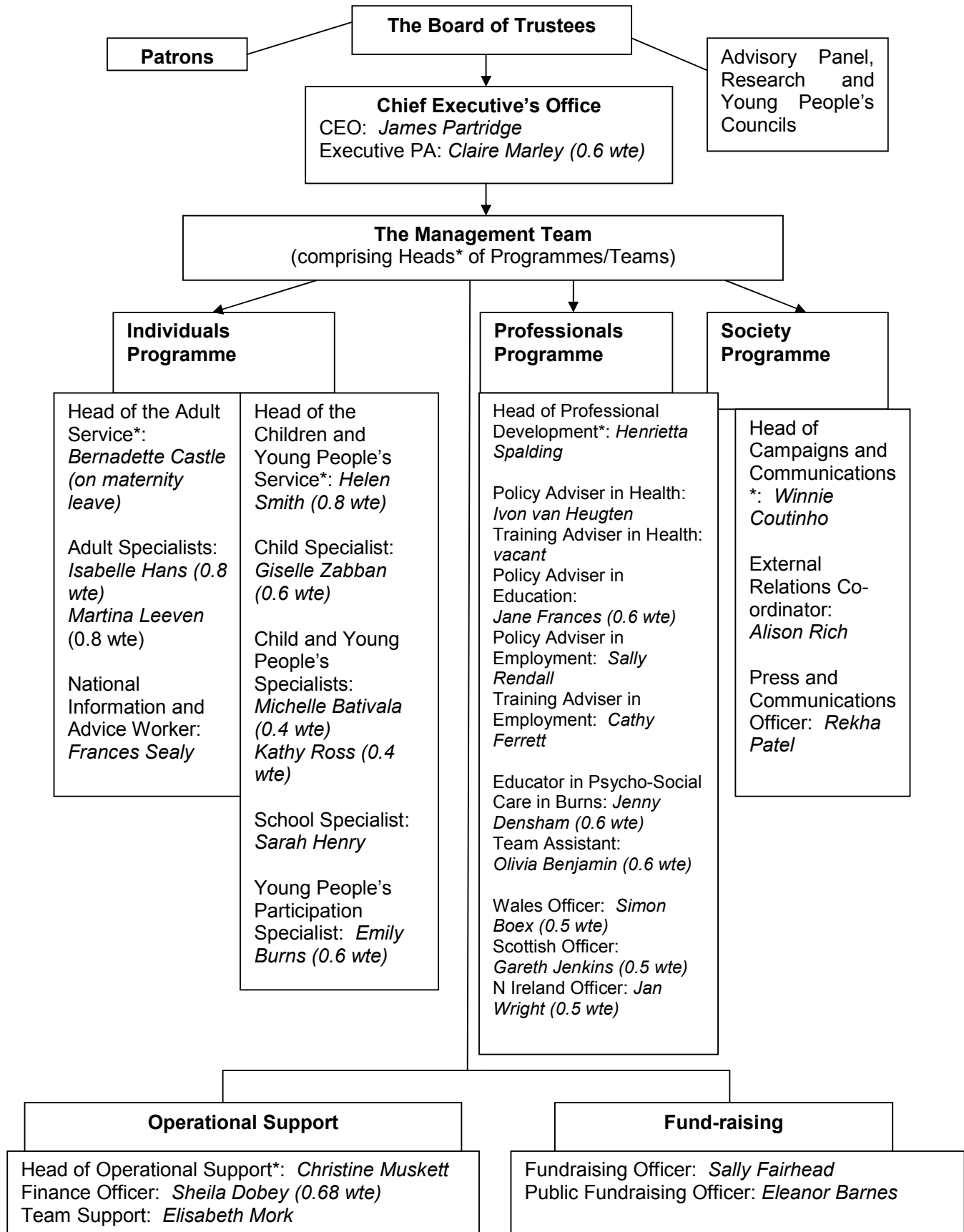
- Fundraising will be challenging: must increase our fund-raising team's size and efforts
- Aim to complete the £1m loan repayment by July 2009
- Take over the whole Squire Centre and invest in its refurbishment, as well as continuing to have a strong administrative team backed up with effective IT and database systems

### International

- Aspirationally, once the loan is repaid, develop our international activities utilising with the strategic framework proposed by Deloitte.

The whole charity will commit, as routine, to the measurement of the outcome of all work in all Programmes in close collaboration with the Centre for Appearance Research and other institutions

**ANNEX 3: Organisational structure, March 2009**



## ANNEX 4: The incidence and prevalence of disfigurement

The word “disfigurement” is used to describe the aesthetic effects of a mark, rash, scar or skin graft on a person’s skin or an asymmetry or paralysis to their face or body. Disfigurement can affect anyone at any time, at any age, from any ethnic group whether from birth, accident, disease or the aftermath of surgery.

There are no official statistics to record the scale of disfigurement, but in 1988 the Disability Survey (conducted by the Office for Population Censuses and Surveys) estimated that there were at least 400,000 people in the UK who had 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 figure has, however, little foundation and has been unsatisfactory as a basis for raising public awareness and advocating for better services.

In the autumn of 2007, *Changing Faces* commissioned a thorough search of all existing studies, data and websites to create a better estimate of the incidence and prevalence\* of disfiguring conditions. This has been conducted by Professor Desmond Julian (retired cardiologist) and Dr James Partridge (MSc (Demography)) supported by the *Changing Faces* Research Council members including Professor Walter Holland (epidemiologist). The survey’s findings will be published in due course in a peer-reviewed journal.

It is very difficult to define a ‘disfigurement’ precisely – and some people do not like the thought that they might be counted as having one. Disfigurement is in the eye of the beholder – and the person themselves. It is well-recognised in the psychological research literature that the extent or severity of a disfigurement does not correlate with the amount of distress it causes. What may appear ‘minor’ disfigurements, especially if they appear in the communications triangle on the human face where other people focus their gaze and attention, can be associated with low self-esteem and self-confidence. Equally, disfigurements that can be hidden by clothing can pose psychological problems.

The aim of the study was to establish a more accurate and sophisticated estimate of the incidence and prevalence of ‘significant’ disfigurement, based on reasonable and tough assumptions and differentiated by the medical causes of disfiguring conditions. Significance was taken as having ‘visibility’, ‘extent’ and ‘location’ dimensions – and is used to indicate ‘significant in psychological and social terms’.

The research has reached the following conclusions:

- 542,000 (or one in 111) people in the UK have a significant disfigurement to the face.
  - 92,000 have congenital or birth conditions like birthmarks, cleft lips/palates
  - 66,000 have disfigurements from accidents such as burns and facial scars
  - 40,000 have cancer-related disfigurements, from surgery for skin cancer
  - 100,000 have disfigurements from facial paralysis including from stroke
  - 220,000 have disfiguring skin conditions like psoriasis, vitiligo and acne
- 1,345,000 (or one in 44) people have significant disfigurement to their face and body.
- 415,500 people are expected to acquire a significant facial disfigurement in the period of a year, some conditions being transient, some life-threatening.

More information on this can be found on our website: [www.changingfaces.org.uk](http://www.changingfaces.org.uk)

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\* *Incidence* is defined as the proportion of new cases of a disorder in a population in a specified time interval and *prevalence* the proportion or number of people who have a given condition in a population at a specified point in time.