

"Improving the Life Chances of Disabled People"

Comments on PM Strategy Unit's Analytical Report from James Partridge OBE, DSc (Hon)

These comments come from two perspectives: one, as Chief Executive of *Changing Faces*, a leading UK charity supporting and representing people with disfigurements, and secondly, as a founding Director of *Dining with a Difference*. Although the perspectives are inter-related, I have separated them below.

Overall, the Report is impressive in its scope and analysis – and we welcome many of the broad conclusions reached. The analytical findings are well-structured, the vision is strong and do-able, and the steps for Government mostly well-expressed. In particular, we welcome the acknowledgement and adoption of a social model approach to these issues with the very sound caveat that over-generalisation is risky for both analysis and policy-making.

Views from Changing Faces

Changing Faces is very concerned that the Report fails to recognise disfigurement within its definition or remit. This is not an impairment-specific criticism.

In 1994 and 1995, *Changing Faces* successfully advocated for the DDA to include disfigurement within its definition of disability – and thus, someone who has a "severe disfigurement" either present at birth or acquired from accident, disease, skin condition or facial paralysis is to be treated under the terms of the Act "as if they had a disability".

There are estimated to be at least 400,000 people in Britain with a "scar, blemish or deformity which severely affects their ability to live a normal life" (OPCS 1988). Although they are not considered conventionally as having an impairment to daily living that requires a physical adjustment of some kind (eg: a sensory impairment – though many do have sight or hearing difficulties). In the case of disfigurement, it is not the physical environment that acts as a barrier, but purely the attitudes of other people that are disabling.

For the last 12 years, we have been working both to empower children and adults with disfigurements of all kinds *and* to transform the attitudes of schools, employers and the media towards disfigurement. In the process, we have been forced to realise just how very deep-rooted are the stereotypes around disfigurement – that people with disfigurements are perceived as sad, outsider figures destined for a half-life as second-class citizens because of their unusual appearance.

We believe these and similar stereotypes are around most of disability especially around mental health and learning disabilities. Whilst these persist, they are the greatest barrier to inclusion and progress. Indeed, we have frequently found that until attitudes are reformed (in any institution we are working with), changes in access, policy and practices are only half-hearted, lip service.

We completely share the Report's view that "attitudes are slow to change". Yes, and because attitudes change is so fundamental, we believe that much more effort and emphasis should be given to attitudinal shifting. We were therefore disappointed that within your Report's analysis and conclusions, not enough attention was given to the role that Government and the public sector can and should play in attitude change – from page 34 to 48.

We fear that your Report's extensive use of the word "*barrier*" is itself unhelpful because it automatically suggests a physical obstacle (steps, access etc) with the implication that if removed, all will be well. We would argue that until the "*prevailing negative cognitive-behavioural paradigm*" (mind-set) about disability is recognised and a fresh inclusive paradigm is positively celebrated, long-term change will not really happen.

At an individual level, many parents with children who have disfigurements make this leap, many people with disfigurements and disabilities do too – they turn what to outsiders is “abnormal/different/disabled” into “normal/OK to be different/able to...”.

Making the parallel *cultural* paradigm shift is what *Changing Faces* thinks the Government, if it really means business in this area, should be looking at in a very strategic way. Is there a long-term strategy that could be adopted, not through special cases or via positive discrimination, that would prompt it? How could the combined forces of the media, education, culture, arts etc be mobilised to make it happen? A big question but one which we think the Government could at least commit to explore; indeed there are hints of some of the elements of it in the Report (eg: involving disabled people at the heart of Government).

Views from Dining with a Difference

Dining with a Difference is a small but very effective change agent – see the attached leaflet. In effect, the *Dining* team is invited by the Board of major public companies (primarily in the FTSE 100) to a private dinner at which disability is discussed in a unique, eye-opening way. Disability as an important strategic business issue in an era of rights, demographic change and tight labour markets is stressed and company-specific solutions are explored.

Two key insights emerge from our four years of experience, both of relevance to this Report:

- Disability is considered in the minds of most senior Executives (and the wider public too probably) as something that happens to people “over there”. Actually, once they have explored the statistics and considered their personal experience, family and friendship group, they almost without exception realise that disability is directly relevant to someone close to them. This personal discovery can be start of the next step on a road to action.
- In all the companies and public organisations we have worked with, there is one common strand: if the top team give and are seen to give active leadership to making change happen around disability (and diversity), things happen. Barclays and many other companies are examples of good practice as you have pointed out in the Report. And the reason for this is that there is top-table leadership, prompted, we like to think, at least in part by the Dining experience...

What this means is that informed/enlightened leadership can make the needed cognitive-behavioural paradigm shift happen in particular organisations.

What this means for Government is that it too has, I believe, a leadership role to play – perhaps through a cross-cutting Disability Champion. I am aware that many Government departments have adopted Equality Champions (eg: the Dept of Health has recently appointed one) but I believe the idea that a Disability Champion is worth exploring further.

James Partridge
23.8.2004