Article

Body & Society

19(4) 3–31

DOI: 10.1177/1357034X13477160
bod.sagepub.com
SAGE

Rewriting Bodies, Portraiting Persons? The New Genetics, the Clinic and the Figure of the Human

Joanna Latimer
Cardiff University, United Kingdom

Abstract

Contemporary debate suggests that the new genetics may be changing ideas about the body and what it is to be human. Specifically, there are notions that the new genetics seems to erode the ideas that underpin modernity, such as the figure of the integrated, discrete, conscious individual body-self. Holding these ideas against the practices of genetic medicine, however, this article suggests a quite different picture; one that does not erase, but helps to keep in play, some crucial tenets of humanism. The article examines how the genetic clinic constructs clinical pictures as new forms of portraiture: assemblages in which multiple and heterogeneous images of bodies and their parts are juxtaposed. Rather than these portraits just making the distributed and hybrid nature of personhood explicit, shifts in ground mean that what is being portrayed is the possibility of a 'syndrome–genotype' relation. At first sight this appears as a straightforward geneticization of the body and the unravelling of the figure of the individual. But the article illustrates how, at the same time as the portraits of syndrome–genotypes are made up of many heterogeneous parts, the clinic still keeps in play an idea of persons that remains, unlike their bodies, much more than the sum of their parts. All the parts that make up the body of the person can still, at moments, be transcended, to refigure the human: the complex individual of humanist thought.

Keywords

assemblage, biopolitics, dysmorphology, genetic medicine, geneticization of the body, humanism, postmodern biology

Corresponding author:
Joanna Latimer, Cardiff University, The Glamorgan Building, King Edward V11 Avenue, Cardiff, CF10 3WT, United Kingdom.
Email: latimerje@cardiff.ac.uk
http://www.sagepub.net/tcs/

> any new possibility that existence acquires, even the least likely, transforms everything about existence. (Kundera, 1996: 36)

This article examines how debates on the new genetics, together with ongoing developments in biological theory, are rewriting the body and thus challenging ideas of what it is to be human. For many years sociologists have been attempting to 'bring back the body' (Frank, 1990), an agenda which involves our deconstructing ideas of persons that previously kept in play the mind/body split. More recent writing, however, signals an era of the 'post-human', due in part to the ways work in the new genetics, or 'postmodern biology' (Melley, 2002: 51) appears to trouble body–self relations.

In particular commentators suggest that a 'geneticization' of the body could lead to a revolution in our ways of conceiving persons as individual. The aim of the article is to challenge this particular way of undercutting the figure of the individual. Any rewriting of the fabric of the body that erodes notions of persons as individual has profound implications for our ways of ordering social relations. For example, Habermas (2003) questions the decoupling of a specifically human nature because of its consequences for the functioning of the many social institutions that rely on notions of individual responsibility, conscience, will and so forth. In addition, while for some the deconstruction of the human represents a potentially liberating ontology of connectivity, there are also profound implications for humanist traditions of welfare.[1] As Strathern stresses:

> Bodily uniqueness is a sign, as much as it is a Euro-American symbol, of autonomy and respect for the person as an individual. But genes are not unique at all – the combination might be unique but the genes are replicas. (2006: 20–1)

The field research drawn on holds the *clinical* practices of genetic medicine against the more general ideas underpinning this version of the post-human debate. The clinic has long been understood as a site that performs[2] the dominant body–self relations that underpin modern biopolitics. Foucault (2003a, 2003b) and Deleuze (1997), among others, have helped to connect the operations of power to ideas of the integrated, discrete body-self. They have shown how modern politics works consciousness through the body, both the substantial body and the body as an idea. They have both explored how the clinic has been

pivotal in this biopolitics of the body. For example, the clinic has helped to constitute how we think the body and the ways in which we think the body constitutes ideas of the normal, the individual, and individual–society relations.

In showing the limits of genetic medicine as it affects the clinic, I question the more totalizing presumptions of any geneticization of the body. Specifically, as Foucault (2003a, 2003b) has helped to illuminate, the clinic is one of the key sites in which the very possibility of the figure of the individual, and the individual–population relation, are produced and reproduced as basic units of modern forms of social organization. It is also one of the key sites through which the new genetics is being embedded in society (Latimer, 2013; Rabinow, 1992).

The analysis in the article thus focuses on the new genetics and the clinic, and illustrates how their coming into alignment does not erase the figure of the individual, but rather helps to keep in play crucial tenets of enlightenment humanism. The fieldwork drawn upon for my analysis describes how the genetic clinic constructs clinical pictures of syndromes[3] as new forms of portraiture: assemblages in which multiple and heterogeneous images of bodies and their parts are juxtaposed. As might be expected, these portraits make evident the distributed and hybrid nature of body parts. Yet this is not to say that all aspects of *personhood* are so encapsulated. Instead, shifts in ground by the clinicians mean that what is being portrayed is the figure of a (pathological) *genotype*. Momentarily, at least, people and their parts are reconfigured by clinical processes as the visible expression of a genotype as the origin of a syndrome. In the article I am suggesting therefore that what these methods of portraiture fabricate is a syndrome–genotype relation.

At the same time as these portraits of a syndrome–genotype relation are made up of many heterogeneous, fragmented parts, the analysis shows how the clinic still keeps in play an idea that persons – unlike syndromes – are much more than the sum of their parts. Specifically, all the parts that make up the body of the person can still, at moments, be transcended, to refigure the human: the complex individual of humanist thought. Consequently, I am concerned with how clinical medicine in any alignments with the new genetics performs the ways in which bodies and persons are being conceptualized. But, unlike other commentators, in basing my analysis on clinical practices over time and across space and differently situated occasions, what comes into view is that any geneticization of the body is neither homogeneous nor totalizing.

In the rest of the article I press these contemporary debates about how the new genetics may be rewriting the relation between bodies and selves against the practices of one site through which the new genetics is being enrolled and translated: the medical genetics clinic. What stands out are shifts in ground that perform persons as at one moment unique and at another as made up of substance that is shared, or, as Strathern (2006) puts it, held in *common* with others. But switches in alignments also afford the clinic moments for the performance of persons as capable of transcending their bodies, despite their genes.

The New Genetics: Rewriting Bodies, Deconstructing the Human?

While the term the 'new genetics' does not completely supersede old ideas about genealogy, biology and inheritance (cf. Brown, 2004), the phrase usually refers to the contemporary proliferation of genetic and reproductive techno-science that appears to create opportunities for new forms of classification and categorization that may or may not break down some of the old classificatory divisions (Rabinow, 1992, 1996). Here there are arguments that this revolution does not just lead us back to old forms of biological determinism. Rather, by offering individual genetic profiles that are also located in a collective gene pool (Flower and Heath, 1993), geneticization of the body may characterize a 'recombinant bio-politics' (Dillon and Read, 2001) that unpicks the fundamental principles of humanism and the polarity of individual–population that underpins the ordering of social relations.

An emergent body of research explores the cultural, political and social significance of how bodies and persons are performed by the practices, artifacts and discourses of medicine at the interface with the new genetics and reproductive technologies (e.g. Atkinson et al., 2006; Brodwin, 2002; Carsten, 2000; Clarke, 1998; Clarke et al., 2010; Martin, 1991; Pálsson, 2007; Thompson, 2005). Specifically, within this tradition, feminist STS and cultural studies scholars, as well as medical anthropologists, are exploring how changes in biomedical understandings of the body may not just be changing disease categories or how clinical medicine works on the ground, but may make explicit new ontologies, particularly of connectivity. This is not to suggest that human materiality, for example DNA, determines human nature. Rather, it is to explore how discoveries in molecular

biology incorporated into clinical science can undo the very body–self relations that underpin so much of western thought. Let me elaborate.

By suggesting how bodies are not, as previously understood, bounded, contained, homogeneous, fixed and integrated entities, the individual whole persons of humanist thought, made up of substance that is *uniquely them*, emergent understandings from the biosciences have the possibility of changing perceptions of the body, and thereby of the existence of human beings. That is, contemporary discoveries in molecular biology seem to trouble the self/not-self division that is the defining feature performed by the figure of the individual body. This can be understood in several ways. First, as Haraway points out, human bodies are not made up of uniquely human substance but are heterogeneous:

> I love the fact that human genomes can be found in only about 10% of the cells that occupy the mundane space I call my body; the other 90% of the cells are filled with genomes of bacteria, fungi, protists, and such, some of which play in a Symphony necessary to my being alive at all, and some of which are hitching a ride and doing the rest of me, of us, no harm . . . . To be one is always to be many. (Haraway, 2007: 3–4)

The new genetics thus puts into play an idea that '[w]ithin "us" is the most threatening other – the propagules, whose phenotype we temporarily are' (Haraway, 1991: 217).[4] Second, breakthroughs made possible because of new genetic techno-science offer ways of rethinking body-persons as made up of substance from a much wider gene pool, and of the body as the temporary and partial expression of a genotype. Within this perspective it is the DNA that is immortal, and the genes that are the 'time travellers', while the body or soma is just the transport vehicle, the hired car, the temporary and dispensable host for their reproduction (Olshansky and Carnes, 2001).

It seems then that the new genetics has the potential to destroy the usual image of the individual that as Strathern (1992: 93–4) has illuminated is *the* trope performed by Euro-American, modernist ideas of kinship.

> A child was endowed with material from both parents, literally formed from parts of them. Yet it was regarded as equivalent to neither mother nor father nor to the relation between them: rather it was a hybrid product in another sense, a genetically unique individual with a life of its own. It was only a part of their life, despite the fact that its genetic material was formed wholly of theirs.

As Melley, discussing Haraway, points out, this is partly because of how postmodern biology 'privileges "biotic components" over the "traditional organism"' (2002: 50). Instead of the '"single unit of masterly control", what appears is a new kind of biological organism that is a "pastiche of multiple centres and peripheries"' (2002: 50–1). Melley goes on to show how, within this perspective, the apparent unravelling of the body-self as unique and individuated is specifically being done by 'nature' and the materiality of bodies 'talking' back in surprising ways, so that postmodern biology is forcing (humanist) social philosophy to retheorize, particularly regarding notions of the agentic subject and the possessive individual.

Martin (2010), for example, in her work on microchimerism and 'cell trafficking' between mother and fetus suggests that, in the history of microchimerism, biomedical scientists have had to struggle with an anomaly that undoes the metaphor of the bounded, individual body-self that forms the basis of immunology theory:

> In microchimeric bodies, cells that are coded as 'not-self' are living and reproducing happily in body-nations that are not their 'own'. In this way, ontologies are shifting in light of the unexpected, as are appropriate metaphors of what the biological (and indeed social) 'self' is. (2010: 25)

This surprise finding about 'fetal' cells living in the 'motherland' (the body of the mother) challenges immunology's underpinning ideas of bodies, persons and the immune system based on the self/not-self division: immunology relies on an understanding of bodily substance (cells) of persons as being a territory that is uniquely their own. What Martin proposes is that emergent understandings have the potential to shift the model of the fetus as foreign, to one that recasts the maternal–fetal relationship in ways that blur the borders of bodies so that individuals re-emerge not as discrete and unique but as 'constitutively intermingled' (2010: 26). Following Douglas's (2003) emphasis on the mirroring of the fleshy and the social body, Martin explores how the migratory character of globalization mirrors this intermingling to trouble the bordering that underpins the politics of nation-states.

Critically, if the heterogeneous nature of a human being's substance is unmasked as not entirely their own (nor even all human), does it become harder to resettle them into the figure of the unique

individual (see also Latimer, 2009)? Specifically, is this an 'ontic politics' (Verran, 2011), in which understandings from the new genetics might help in the process of unpicking the ideas that bind the body to the figure of the possessive, autonomous individual and the dominant power relations that flow from this binding? But here questions also arise as to what then happens to persons if the figure of the individual is deconstructed and refigured as the constituents of a phenotype, and this partial phenotype is merely the material expression of an informational pattern, a genotype, made up of elements of information coming from a gene pool that is common to many, even non-human, others?

The Field Study

In putting into question how the genetic clinic puts into play new conceptions of body-persons that unpick the figure of the individual and the idea of the human, I explore how processes of diagnosis and differentiation that characterize clinical genetics, in the UK at least, perform the relation between persons, bodies and selves. In this turn to clinical practices I am departing from the studies discussed above in that I examine the extent to which ideas made possible by the new genetics do or do not intermingle in the everyday practices of the clinic.

The material presented about the practices and processes of clinical genetics comes from a study of dysmorphology, which was being promoted as an emergent field of expertise fundamental to the discipline of genetic medicine. The examples drawn upon in what follows arise from an extensive ethnographic study carried out in the clinical genetics service of a major UK teaching hospital providing clinics across one large region of the British Isles using a multimethod approach. The study tracked dysmorphology through all aspects of clinical and academic process. One aspect of the study involved the participant observation of two clinical genetics teams, including weekly team meetings ($n = 52$), home visits carried out by the genetics specialist nurses ($n = 7$) and clinical consultations ($n = 140$). A number ($n = 10$) of academic and educational encounters between professionals were also observed, such as local, national and international meetings of clinical and trainee geneticists and genetic scientists, including 'Dysmorphology Club', at which dysmorphologists present and debate their cases. In addition, I undertook

qualitative interviews with seven internationally renowned clinical geneticists who worked in seven other regions in the UK, identified by peers as experts in dysmorphology, and examined various 'syndrome' or dysmorphology related websites, including dysmorphology databases as well as dysmorphologists' published papers. Including these other registers of dysmorphology process, discourse and practice provided cross-checks and balances in my descriptions and interpretations of the everyday work of the clinic under study, to ensure that these are both valid and to some extent representative. Although I am not specifically drawing on the material here, interviews with patients and their relations referred to the genetic service ($n = 18$ families) were also undertaken.[5]

In the rest of the article I analyse how the work of categorizing and diagnosing within dysmorphology produces and reproduces not just diagnoses but particular kinds of bodies and persons. My focus is specifically on when and how clinical medicine aligns with the new genetics to put into play genetic explanations for disease effects and the extent to which these diagnostic processes reconstitute dominant body–self relations, and when they do not. My presentation here of the kinds of bodies and persons being performed through differently situated clinical practices has been validated through cross-checking interpretation both within differently situated occasions and registers (such as clinical consultations, team meetings, presentations at conferences, published papers and websites), as well as across these different occasions and registers. Here I am interested in what the practices, artifacts and discourses assembled together in clinical process perform. By the term 'perform' I not only mean that we can understand that clinical process is a site of cultural performance (Frankenberg, 1986), I am also emphasizing that the ways in which the artifacts constituted and used in the clinic circulate particular cultural meanings and relations – in this case between bodies, selves and personhood. These meanings are often implicit (Douglas, 1975) and are the effects of processes and practices, particularly how materials are used and what they are *made to mean* (Latimer, 2004; Strathern, 1995).

Dysmorphology's Portraits

Experts in dysmorphology define themselves as concerned with the study of abnormal *forms*, and as closely concerned with human

growth and development. Thus the dysmorphology clinic works the boundaries between genetic techno-science, embryology, a discourse of normal child development, paediatric medicine and the family. Dysmorphologists identify patterns in facial and other features, and in clinical and family histories, in the construction of what they call 'syndromes'. At the time of the study there were over 3000 syndromes recorded in dysmorphology databases. The clinical enterprise is particularly focused on differentiating whether clinical features have a genetic base or are an effect of a perinatal event, such as fetal alcohol syndrome. Patients are mainly babies, children, their parents and other relations. Some of the children referred to the clinic are extremely affected, including by severe intellectual and behavioural as well as physical disabilities.

In dysmorphology many photographs and slides of children, parts of their bodies and photographs of other family members are juxtaposed with other visual imagery in the construction of a clinical picture in very specific ways. These clinical pictures are assembled by clinicians as ways to detect the presence of a syndrome, or of an aberrant gene. It is the specificity of how the clinic constructs these clinical pictures that I want to examine as a form of portraiture.

Medicine's use of portraits as powerful technologies is nothing new: there is a long history of the use of images in clinical work, particularly in the science of visualizing disease as method and as ways of knowing bodies. Gilman (1988), for example, has shown how clinical science has a history of deploying portraits of 'affected' persons in the work of establishing pathologies and teaching recognition of diseases. Medical textbooks are full of such images. These portraits are classic depictions of a human figure in a specific pose, such as Londe's portrait of hysteria (Figure 1). The figure is taken not so much to represent him- or herself, but as representing the disease category to which they are being assigned: the figure is being read as signifying the pathology.[6] But engaging with clinical pictures as forms of portraiture is also important because, as Jordanova suggests (2000, 2003), portraits are mobile objects that circulate culturally and socially specific ideas about body–self relations and personhood. For example, Albert Londe's portrait shows that the effects of hysteria are totalizing, so that the woman embodies the illness. But the form of the portrait also individuates, not just hysteria, but the body-self and personhood.

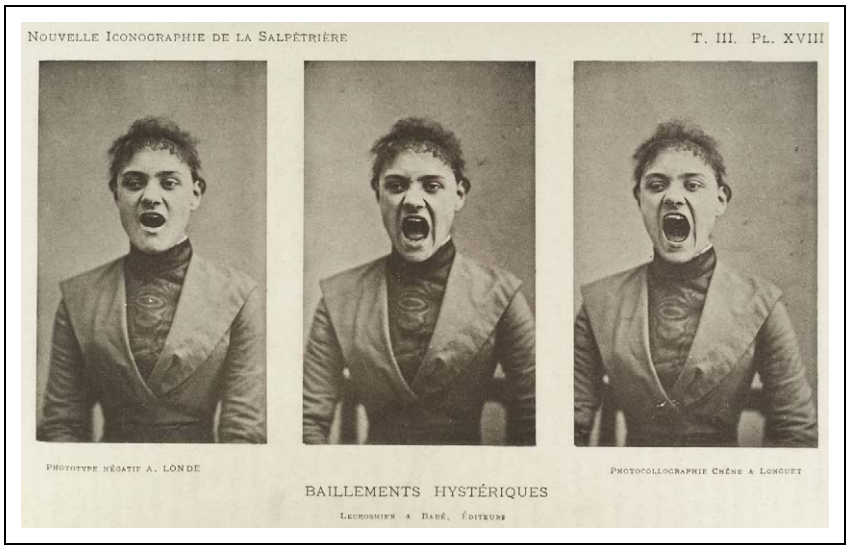

Figure 1. Three photographs in a series showing a hysterical woman screaming, c. 1890. By Albert Londe. *Nouvelle iconographie de la Salpêtrière: Clinique des Malades du Système Nerveux*, vol. III, Plate XVIII. LeCrosniesr et Babe, Libraires-Editeurs, Place de l'Ecole de Médecine, Paris, 1890. With kind permission of the Wellcome Library, London.

Considering how the practices of dysmorphology construct its portraits can thus help us to understand the very specific ideas about the relation between bodily substance and the gene to address the question of whether dysmorphology rewrites bodies in ways that seem to depart from those dominant ideas of body–self relations that underpin the idea of the human.

In dysmorphology, clinical geneticists' processes of diagnosis assemble and juxtapose different and multiple images of people and their parts and their relations. Some of these images derive from the examination of the child during consultations. Following an intense history, a typical dysmorphology examination 'starts from the top' (Consultant dysmorphologist, field notes, clinical consultation with Sheila). They carefully inspect the head, the face, the tongue, hands, trunk and back, joints, feet, and take measurements of head circumference, height and weight. They are looking at the shape, size and position of features, sometimes in relation to one another. After the examination the clinician frequently takes photographs of any distinctive features, and may also ask parents for photographs of the

child when they were younger, and of siblings and other family members.

Diagnoses are developed over time at clinical and academic meetings; they are almost never offered immediately at a clinical consultation. The diagnostic process includes the assemblage of images and their juxtaposition with other clinical materials, such as scans of organs and bones, blood and cytological tests, and medical family trees or pedigrees. This process of assemblage and juxtaposition can be seen across local clinical meetings, in clinical databases, and in poster and oral presentations at national and international conferences. At moments of assemblage – whether in clinical meetings or at academic occasions – certain forms, shapes and distributions of bodily features (faces, hearts, hands, feet, hair, genitals, brains, skin) are designated as abnormal or unusual. Sometimes clinicians talk about a child as an 'FLK' – a 'funny looking kid' – or as 'looking a bit chromosomal'. What clinicians are doing is associating features together to see if there is a pattern – a pattern that corresponds to the defining features of a syndrome.

Establishing whether the features displayed can be taken to represent a syndrome is a complex process. The pattern-making associates different parts of bodies with each other across systems, such as specific shapes of eyes with abnormalities in brain shapes, and so on and so forth. Many syndromes involve developmental problems: flesh develops in abnormal ways to produce abnormalities in the shapes of organs, such as the brain, and other fleshy parts. It is these abnormal shapes that produce abnormalities in what the clinicians designate as the development of the child (physical, behavioural, intellectual). Differentiating the cause of abnormality includes establishing whether the way someone, or one part of them 'looks' is 'in the family', the sign of a syndrome or a distinguishing feature of an individual (see also Featherstone et al., 2005; Latimer, 2007a). Here, dysmorphologists compare looks and features across family members and hold them against databases of syndromes.

Clinicians draw upon these clinical methods of assemblage and juxtaposition to differentiate when what is abnormal or unusual about bodies, parts, persons and even families, represents a phenotype.[7] This is because for the most part, there is no genetic technology (molecular test) that can make anomalies visible at the molecular level (see also Reardon and Donnai, 2007). In this way, through their

performance of rational detachment, geneticists constitute patterns in the way a person and/or the members of their family look as a sign: as the defining features of a syndrome. But the way that these features across families are juxtaposed also performs relations.

The relation that gets implied in how dysmorphologists construct their clinical pictures is between the particular features of a syndrome, the notion of a phenotype, and, as such, perhaps the expression of an atypical, aberrant genotype. At moments, it is this relation, the syndrome–genotype, that dysmorphology's portraits evoke. The aberrations may be as tiny as a single gene defect. For example, where, to use the expression of one expert, 'a bit of chromosome has fallen off and landed in the wrong place'. The suggestion implied by how geneticists assemble their clinical pictures, then, is that how people and their bodies look and function (the phenotype) may not just be evidence of a syndrome but also that the syndrome is the effect of a specific aberrant (but as yet invisible) genotype, a syndrome–genotype relation.

The following extract helps illustrate how portraiting the possibility of a syndrome–genotype relation works in practice. A case is being discussed at a local clinical meeting, in which slides (see also Shaw et al., 2003) are being shown, in one of the genetic clinics that we studied. Present at the meeting are Dr Little and Dr Smith (consultant geneticists), Dr Grey and Dr Milne (specialist registrars in genetics).

Dr Grey sets up the projector. They go through a number of new referrals as well as ongoing cases. Dr Grey moves the slides on to show a picture of an 8-year-old girl, Poppy, with short brown hair grinning into the camera. This is the case Dr Little is very excited about.

Dr Smith: Would anyone like to make a diagnosis?

Dr Little: This is Poppy, she is doing very well, she's in a regular class, she has some help but is not coping. She came with her mum and dad who want to know what's wrong. Poppy was referred by a number of doctors and by a community health worker who suggested I should see her and mentioned that there was something odd about mum too.

[Dr Little projects a slide of a head shot of Poppy, then a slide of her hands, palms down]

Dr Grey: Short finger.

Dr Little: A short finger, how about the nail? . . . [no comment from the others] it's more deeply embedded than the others.

[Slide of Poppy's hands palm facing up]

Dr Milne: Foetal finger pads . . .

Dr Little: Short thumbs.

[Slide of left foot]

Dr Little: Short toes and broad.

Dr Milne: Shapeless feet.

Dr Little: Tiny, smaller than her younger sister . . . also the toenails are deeply embedded, the parents commented on how difficult it was to cut them.

Up to this point the team have been looking at slides of Poppy, and juxtaposing images of her face, her profile, her hands and fingers, and her feet. Although asked to make a diagnosis, no one proffers a suggestion. Then the slide show moves on.

[Slide of the child's mother – head shot of woman in her 30s with short curly hair and large eyes framed by large glasses – the doctors all exclaim when they see this slide]

Dr Little: She has large eyes, lateral aversion of the eyes [she demonstrates by pulling her eyes to the side to get an oriental look], her height is 1.49 centimetres. I got hold of the mother's baby notes, she was seen by lots of paediatricians because of her short stature and her pictures were shown at national dysmorphology meetings in the [19]70s. So that's mum.

[Side profile of the mother – Dr Little comments on her prominent eyebrows that have high and large arches]

Dr Smith: We're talking about Kabuki aren't we, but the nose isn't.

Dr Little: The girl (Poppy) does [have the nose]. I'm encouraging mum to get some pictures of her(self) as a child.

The moment that Dr Little puts up a slide of Poppy's mother the rest of the team exclaim – there is what the dysmorphologists I interviewed refer to as a *gestalt* moment – a moment of sudden recognition. This is when Dr Smith offers a diagnosis: 'We're talking

about Kabuki.' Poppy has the nose but it is her mum who has the eyes and brow. So the defining features of Kabuki are seen in the juxtaposition and assemblage of features distributed across the two bodies assumed to be biologically related. The team go on to discuss the significance of the case:

[Side profile of Poppy]

Dr Milne: There aren't many [Kabuki] across generations, Owen (another geneticist) has an unconfirmed one.

Dr Little: There is no actual report in the literature with a generational aspect [she adds that it would be a good case for someone to work up].

[Dr Smith briefly mentions a contact – her supervisor in the US who worked with the person who discovered or first wrote about Kabuki – to see if they are still doing work in this area. Dr Little doesn't pick this up]

Dr Little: Mum's got the full house really.

Dr Milne: How about Manchester?

Dr Little: I think they've given up [doing work on this syndrome]

[Slide of Mum's profile and hands]

Dr Little: See the frontal finger pads and the tiny fifth finger ... can I take that to [London meeting of Dysmorphology Club]?

Dr Smith: Yes.

Dr Little: It's really helpful to see an adult, many die of renal failure, that's the worry. [She goes on to mention some of mum's renal symptoms from the past, for which she's had no treatment or examinations] So that's a worry, so we need to look at her kidneys.

Dr Smith: What's her IQ like?

Dr Little: Coping, just, in the 70s I think.

Dr Smith: They're a good family.... I can see if the Professor [Kabuki] in Japan is still doing work in this area.

Dr Little: They would be a good family to do, mum is so dramatic, I have no doubt in my mind.

> [Dr Grey moves the slides on to a head and shoulders shot of a pretty young girl with blonde hair smiling into the camera]

To make their portrait, clinicians assemble slides of Poppy's face, hands and feet, and juxtapose these with slides of her mother's face and hands. They make their readings of these features, that the toes are short or the eyes are down-slanting, and align these with other materials they have collected and make present as significant (such as a history of kidney disease, records of height measurements). They put this together with records of Poppy's IQ and problems with development – she's not coping at school even with help. The parts they are interested in are being constituted as distinctive in terms of their shape and form (eyes, head, toes, hands, fingers, nails, height), while Poppy's conduct is assessed against norms of intelligence and development. The implication is that her brain like her hands is malformed in some way.

The doctors are excited because the moment the slide of Poppy's mother's face is shown what they are seeing in Poppy falls into place as the defining features of Kabuki. In the case of Kabuki Syndrome, which is rare, there is no so-called definitive evidence, no molecular test results that confirm the clinical picture as the phenotypical expression of an aberrant genotype (cf. Kara et al., 2006). What I want to suggest, therefore, is that what is being implicitly performed here is not just the defining features of Kabuki. Rather, through the ways in which the features are assembled and juxtaposed from *across the bodies* of a mother and her child, what is being suggested is that Kabuki distributed across two related bodies suggests something in common at the genetic level. Constituting a relation, between how Poppy and her mother look, the syndrome (Kabuki), and a genotype thus suggests something more than the syndrome itself. The portrait constructed of Poppy and her mother suggests that there is something in common at the genetic level, and (possibly, partially and provisionally) a syndrome–genotype relation, that cannot yet be made visible by molecular tests. This is important because most recorded cases of Kabuki are seen as sporadic, or *de novo* events, and rarely have familial cases fitting autosomal dominant inheritance been documented. I want to press therefore that it is the incompletion and provisionality of the portrait of Poppy and her biological relation, her mother, that is

important here: it gives opportunities for suggesting what is not yet known and what cannot yet be fixed.

Dysmorphology's portraits thus conform in some ways to the science of visualizing disease mentioned earlier and described so well by Gilman (1988). But there are differences of real significance in method and subject matter. The different visual and textual representations of *different* persons, their relations and their parts, are assembled and juxtaposed: the features of a syndrome–genotype are not locatable in one body, in one individual, but across different bodies (see Figure 2 for an example). The syndrome and its cause (an aberrant phenotype) are distributed. What I describe here is also I think different from clinical process in Mol's (2002) 'body multiple'. In the body multiple the clinic creates a perspective that coordinates all the fragments and heterogeneous parts into a hybrid yet settled and integrated form, a diagnosis such as atherosclerosis of the leg. This form, as in Gilman's analysis discussed above, settles into a single body that can be taken to *represent* a disease category. In contrast, in dysmorphology, the heterogeneity and complexity does not always settle into the figure of an individual, as representative of a diagnosis.

The portrait in dysmorphology does not always reduce to the figure of an individual, rather the figure of a syndrome–genotype relation emerges in the partial connection between the assemblage and juxtaposition of materials deriving from different bodies. In the clinic the portrait makes a (temporary) space that cannot (yet) settle all the division and connections between all the parts across different bodies. And it is this that is the defining feature of some of dysmorphology's portraits. The complexity and heterogeneity of the defining features of a syndrome *need to be distributed* for them to stand as a phenotype, and the visible expression of the syndrome–genotype relation. Critically, what is implicit in these juxtapositions and dysmorphologists' readings of them, is that there is something about the substance of the bodies of individuals that is not unique to them, but is shared, or at least held in common, to use Strathern's term. What is exceptional is being able to make the portraits show that it is not simply a disease that is shared, rather it is the common genetic substance, the genotype, that *is* pathological, and that the syndrome is the expression, or phenotype, of this common genotype, distributed across different bodies.

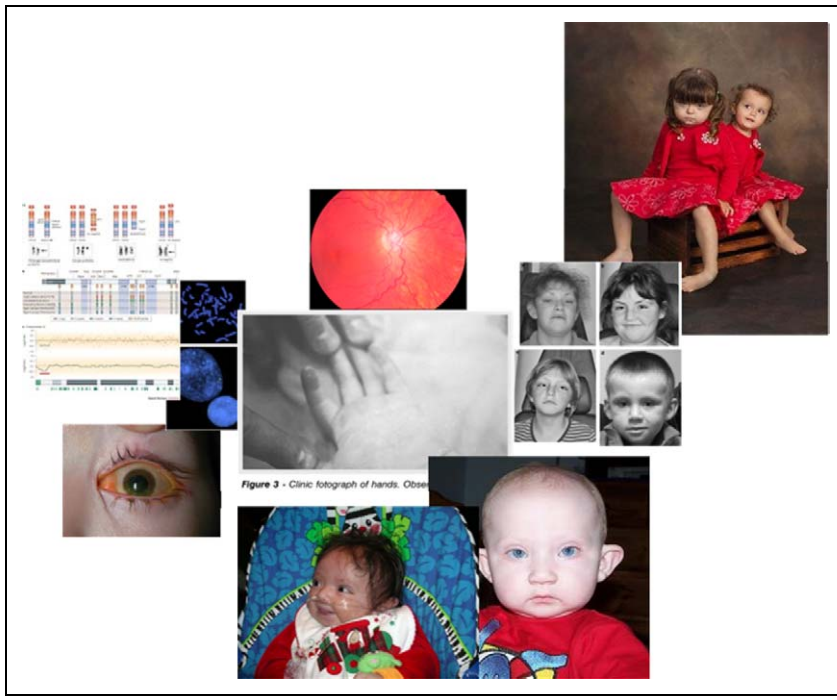

Figure 2. Making a portrait of Kabuki.

Persons in Dysmorphology

As already discussed, questions arise over what kinds of body-persons get produced and reproduced in the relationship between geneticization processes, the clinic, the body and cultural conceptions of personhood. At moments of portraiture dysmorphology process seems to efface those body–self relations that are performed by the figure of the individual and that underpin modernity. But gene medicine would be nothing if it was only concerned with us as dehumanized – as biologically determined effects, made up of fragments, coming from a gene pool, so that the body-person is merely a temporary home for the DNA that will be passed on, 'reshuffled' (Olshansky and Carnes, 2001) to take shape in other forms down the line. Rather, what dysmorphology's portraits perform is that it is the syndrome–genotype that is made of fragments, not persons. Let me illustrate.

At times clinicians and parents together bring into play many different ways of giving the child as an individual human being presence. For example, clinicians frequently refer to a child as 'unique'. But more importantly, parents and clinicians in their interactions attribute

agency to a child, as in the following extract in which Dr Jones and a mother discuss the effects of Ritalin on her son, Fred:

Mother: Getting to sleep is a problem [she describes how difficult it is to get Fred into bed – she has to stay in the room with him until he is asleep; when he stays with his grandmother, he is allowed to sleep in her bed with her].

Dr Jones: On the one hand he doesn't like to be on his own, but he also likes to have a grip on you.

In the doctor's characterization of Fred as 'having a grip' he is being imputed with willpower and desire. At such moments, dysmorphology switches grounds. At one moment, in their alignment with the gene, dysmorphologists perform a detachment, a gaze, that constructs portraits of children and their families that can be made to represent a syndrome and, in the suggestion of substance in common, a syndrome–genotype relation. But at other moments dysmorphologists do more than this: they reinstate persons as much more than the sum of their bodily parts.

In the following extract the team are discussing a child who has just left the clinic, David, an 8-year-old boy with seizures, motor problems and severe developmental delay. Here, even in the case of a syndrome that is so very pervasive across systems, David is reclaimed as a person who is both an effect of and yet as more than his genotype:

Dr Smith: Isn't he lovely?

Dr Jones: Fab, you just get glimpses ...

Dr Smith: ... of what he could be like. Do you think he'll ever speak?

Dr Jones: No, he can communicate though. He has a good understanding of how the world works and how to get people to do what he wants.

Dr Smith: The majority of kids with polymicrogyria are very happy children.

Dr Jones: So chromosomes 21 and 22.

Dr Smith: Yes, I expect them to be normal but worth looking for. There's one x-linked gene where they have narrowed down where

it could be, that will be interesting for him, he fits that mould. It would be useful for the daughter, and people like to know why.

Dr Parry: If they don't find it they are chasing rainbows.

[Dr Smith goes on to explain David as a 'classic polymicrogyria' – dribbling, gait, no speech, developmental problems, coordination problems, epilepsy]

Sometimes you just get glimpses of what David could be like. As a normal, lovely child, living a happy family life. He fits the mould of an x-linked genetic problem, and he is a classic case of polymicrogyria, but David, after all, can transcend his bodiedness, because he has consciousness: 'No [he'll never speak], he can communicate though. He has a good understanding of how the world works and how to get people to do what he wants.'

At the same time, then, as the face of a child may be effaced (Bauman, 1990) by the genetic, the actors responsible for them – the clinicians, the parents – are not effacing their humanity even as they constitute their abnormality. It is the syndrome–genotype that does that. This means that at the same time as clinicians draw upon a notion that the child's condition is biologically determined rather than socially or culturally conditioned, they hold to an idea that there is an essence to persons, that people have a real nature, that a child is unique and essentially human, despite abnormalities of appearances, appearances on the surface and in the depths of the body. In these ways the integral, discrete body is what helps to create the figure of the individual, but the individual, to be truly human, and transcend their bodiedness, must be able to 'disembody'. In this, distinguished by the fact of consciousness, David is reaffirmed as much more than the sum of his bodily parts, common or not.

Discussion: The Double Figure

The current article has examined not only when geneticization of the body is in play in the practices of the clinic, but also when it isn't. The focus has been on how the clinic, and the production and reproduction of body-persons enacted through clinical practices, acts as one site in which cultural conceptions of what it is to be human are instituted in a post-genomic era. As has been seen, the clinic switches alignment, from the gene to the family, to hold other ways of thinking the human, and persons, in play.

The 'defining feature' of humanist thought, to draw on Jordanova's (2000) productively ambiguous phrase about portraits, is the double figure of an individual consciousness incarnated within its own distinctive and recognizable corporeality. At one moment a person is deeply connected to Enlightenment ideas of their human nature being individuated, which involves the possibility of agency, responsibility, autonomy, subjectivity and choice (Strathern, 1988, 1991, 1992, 2006). At other moments it is their corporeality that makes them distinctive and can set them apart.

The relation between the integral, contained, corporeal body and that of the autonomous individual helps perform the figure of the human. This figure of the human is the cultural icon that underpins most contemporary forms of social organization in the West, including sociological theory itself (Skeggs, 2004, 2011; Strathern, 2006). But alongside this idea of the individuated body-self, runs the paradoxical and parallel seam of western thought that detaches rationality from the body: the individual, at moments of choice and autonomous decision-making, to be rational, must have knowledge from a singular, undivided perspective, a perspective that stands outside the plane of personal (that is bodily) action (Latimer, 2007a; Strathern, 1992).

Against notions of the integral, contained body, individuals, to be fully human, also have to demonstrate a capacity for detachment. To attain the singular perspective of rationality, 'man'[8] must be able to *disembody*:

> Many features of contemporary knowledges – knowledges based on the presumption of a singular reality, pre-existent representational categories, and an unambiguous terminology able to be produced and utilized by a singular, rational, and unified knowing subject who is unhampered by personal 'concerns' – can be linked to man's disembodiment, his detachment from his manliness in producing knowledge or truth. (Grosz, 1993: 205)

Paradoxically it is the figure of the person as integral body *and* a unique discrete consciousness that helps to portray the individual as human. To be fully human, and transcend their bodiedness, the individual must be able to detach rather than simply 'disembody', as many have read Descartes (Foucault, 1979). Yes, it is a capacity to transcend the body that distinguishes humanity from its animality,

but, in the western tradition, it is nonetheless the *detachment* of consciousness that is the defining feature of human exceptionalism and potency.[9]

The human, once distinguished by this detachment of consciousness, is thus able to settle into a complex whole. Curiously it is not the envelope of the body, its form that can be caught in paint or a photograph, so much as it is this signing of a detachment of consciousness from bodily experiences that defines the individual. Yes, representations of the corporeal body must take up most of the painting, photograph or sculpture, but it is the capture of the character (the eyes, stance and gesture) that enliven the flesh and make these more than a representation of a corpse. To be seen as human, persons must exhibit characteristics, such as willpower, desire, vulnerability or moral strength.

The figure of the individual is thus performed as a distinctive person who is much more than the sum of their bodily parts. This doubling of figures is one of the paradoxes of dominant body–self relations. Rodin's sculpture *The Thinker*[10] appears to depict this paradox.

At some moments clinicians bring into play grounds that displace bodily biology as that which determines personhood, and re*affirm* a child's and, as I have suggested, their own humanity.[11] Put simply, clinicians bring into play that crucial move in humanist thought: the moment when the figure of the individual is performed as transcending their bodiedness. In other words, grounds are still available, and are put into play, through which the personhood of people such as David can be figured *as* human, because they are much more than the sum of their bodily parts. At other times, however, clinicians, as they protect the humanity of the present child, will not hesitate to agree that reproducing such a child might need to be avoided; that is why the doctor mentions that David's sister needs to know more about his diagnosis, in case it has implications for her own reproductive future.

Concluding Comments

Drawing on an ethnography of genetic medicine, I have explored the interaction of genetic science, the clinic and Euro-American conceptions of personhood. I have discussed how there is debate in the

social sciences about how the new genetics is changing ideas of what it is to be human, particularly how commentators predict that 'geneticization' may rewrite the body in ways that will lead to a revolution in our ways of conceiving persons. This rewriting is said to hold possibilities for the deconstruction of the fundamental principles of humanism and the polarity of individual–population that underpins the ordering of social relations. Specifically, there are notions that the new genetics seems to undermine the ideas that underpin modernity, such as the figure of the integrated discrete individual body/self.

In the article I have held these ideas against the practices of genetic medicine. Rather than a straightforward geneticization of the body, including the deconstruction of the figure of the individual, the article has shown how an alignment of the new genetics and the clinic may extend possibilities for the performance of medicine as, at the same time, it does not exclude but helps to keep in play some crucial and basic tenets of Enlightenment humanism.

Specifically, the article has shown how the genetic clinic constructs clinical pictures as new forms of portraiture: assemblages in which multiple and heterogeneous images of different people's bodies and parts of their bodies are juxtaposed. However, rather than these portraits making explicit the distributed and hybrid nature of *personhood*, shifts in ground mean that what is being portrayed is the figure of a syndrome, and the possibility of defining the features of a *syndrome–genotype* relation. Within the perspective provided by the alignment of the clinic and the new genetics, the bodies of children and their biological relations, ever more anatomized, are fragmented into objects, made to represent a syndrome, or even, where possible, a genotype. Geneticization of the body at these moments risks not deconstructing but destroying the human, and sets back other, more social ways of deconstructing 18th-century notions of the individual that we have inherited.

It seems then that what these portraits portray is that it is a syndrome–genotype relation, rather than a person, that is multiply constructed out of fragments. But, at the same time, the article shows how the clinic still keeps in play an idea that people like the boy David are, unlike their bodies, *much more than the sum of their parts*. Specifically, all the parts that make up the body of the person can still be transcended at moments to refigure the human: the complex individual of humanist thought. This is important because, as

Haraway (2007) reminds us, the humanist production of the individual includes notions of human rights that are critical to social justice, and that can help rescue those categories of persons at risk of social exclusion, marginalization, violence. I want to emphasize, then, how the double figure of the human brought into play in the clinic protects against individuals like David being constituted as so non-human as to become what Haraway describes as 'killable'.[12]

Portraiture thus performs the clinic as able to detect the origins of the form of bodies and their parts, and all their concomitant troubles, from their appearance. But it also helps to remind us that appearances are, after all, as Marx suggested, deceiving:

> If the essence and appearance of things directly coincided, all science would be superfluous. (Marx, 1991: 956)

To be sure advances in genetic science offer different ways to see the body. Simultaneously, however, in its alignment with the new genetics, the clinic reinvigorates itself as a protagonist of the human, not the post-human, and revives the notion that persons are much more than simply determined by their biology. It is this motility, this capacity to switch grounds, that helps medicine in its alignment with the new genetics reinvigorate its role as what Foucault (2003a) described as the queen of the *human sciences* rather than the *life* sciences.

Funding

Thanks to the UK Economic and Social Research Council (grant number R000239863) for funding the project from which the material in this article derives, and to my collaborators in the original research.

Notes

1. I am thinking here of Foucault's examination of how the clinic as a social institution is central to the apparatus of nation-states that allows for the protection, as well as the enhancement, of people and their bodies (see also Hewitt, 1983).
2. Here I am borrowing a notion of performativity from Michel Callon, who states that 'a discourse is indeed performative … if it contributes to the construction of the reality that it describes' (2006: 7).

3. A syndrome is the association of several clinically recognizable features, signs, symptoms, phenomena or characteristics that often occur together, so that the presence of one or more features alerts the physician to the possible presence of the others. Specific syndromes tend to have a range of possible aetiologies or diseases. A familiar syndrome with notable 'dysmorphic' features is Down Syndrome.
4. Propagules in sexual reproduction are seeds.
5. Publication of the study has included exploration of family participation, experience and resistance in the construction of diagnoses (Latimer, 2007a, 2007b), the significance of spectacle in genetic medical practice for sociological understanding of the clinic (Featherstone et al., 2005), and the relationship between the clinic and genetic techno-science in the production of knowledge (Latimer et al., 2006).
6. While elsewhere colleagues and I have shown how dysmorphology draws on and out of this tradition of the display of bodies and images in medicine (Featherstone et al., 2005) to illuminate the visual culture of the clinic (cf. Atkinson, 1995), in what follows I examine the specificities of how dysmorphology constructs its portraits.
7. A phenotype is for geneticists the way that a genotype is manifest: it is the substantial or fleshy expression of a genotype, a specific arrangement of genes. So that things like low IQ, a big head or the distribution of hair could be an individual feature, or in the family, or a sign and evidence of a syndrome. If a feature is part of a pattern of features, and is judged to be evidence of a syndrome, the question arises as to whether it is genetic and whether, if it is genetic, it is inherited. If it is inherited then there is the question of risk, and whether it can be passed on down the generations and through a family line. A part of dysmorphologists' work includes what they call genetic counselling: assessing whether a genotype that produces a syndrome represents an inherited or an individual aberration – a *de novo* event affecting the genetic make-up of an individual, or an aberration that is present across a biologically related family. In doing this they can offer an opinion regarding the risk of the syndrome occurring in other members, either more offspring from the parents of the affected individual, or in terms of their brothers and sisters, or their own children (see Latimer, 2007a, 2007b).

8. As Lynda Lange (2003), in her essay on Aristotle's biology notes, in the phallocentric worldview there is a conflation of male and human, with woman's biology rendering her animal and irrational.
9. Agamben (2002) draws attention to a double paradox here – classical and medieval religious texts portray how, at the moment of their return to paradise, humans are restored as animal, because it is their consciousness that is both a cause and effect of their fall from grace.
10. Musée Rodin, http://www.musee-rodin.fr/en/collections/sculptures/thinker (accessed January 2013).
11. The clinic has long been a site in which body–self relations have been performed. As Leder (1990) asserts, in many ways the body in medicine as lived is absent, except as a corpse. Rather, the body is only interesting as a site for the location of disease.
12. In a conversation with Paul Rabinow I began to understand how Haraway's project in *When Species Meet* could be understood as a manifesto of connectivity with non-humans that brings them into the fold of the best of humanist thought and institutions.

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Joanna Latimer is Professor of Sociology at Cardiff University School of Social Science and the ESRC Centre for the Social and Economic Aspects of Genomics (Cesagen). She has published widely on medicine, science, the body and culture, and contributed to publications at the cutting edge of social theory, including on the art of dwelling (*Space and Culture*) and a special issue of the *Sociological Review* entitled *The Politics of Imagination*. Books include *Un/knowing Bodies* (Wiley-Blackwell, 2009, with M. Shillmeier) and *The Gene, the Clinic and the Family: Diagnosing dysmorphology, reviving medical dominance* (Routledge, forthcoming). She is editor of the *Sociology of Health & Illness*, is on the board of the *Sociological Review* and is in process of editing a special issue of *Theory, Culture & Society* on relationalities among different kinds.