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In/Exclusion in the Clinic: Down's Syndrome, Dysmorphology, and the Ethics of Everyday Medical Work

Joanna Latimer and Gareth M. Thomas

Abstract

In this article, we draw on two clinical ethnographies to explore how mundane social practices, affective processes, and cultural materials (re)produce divisions and forms of in/exclusion. By treating everyday life and routines as serious categories of analysis, we identify how power relations are accomplished and how persons/future persons – namely the ‘dysmorphic’ child or the foetus who has or may have Down’s syndrome – are constituted as un/valued or in/excluded. In relation to dysmorphology, we show how the living dysmorphic child is given shelter but future reproductions of such children are enacted negatively and as to be avoided. With reference to Down’s syndrome, we capture how the condition is made absent in the antenatal clinic and constituted as a negative outcome. In sum, we recognise how exploring the micro and everyday reveals who/what is valued and how particular ways of being in the world are threatened, denied, or effaced.

Keywords

bodies, disposal, exclusion, genetics, hospital ethnography, inclusion, motility, power, reproduction, sociologies of everyday life

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Introduction

This paper explores how everyday life in the clinic is productive and reproductive of ideas around persons, kinships, and being human, with profound implications for the make-up of contemporary society. To exemplify our argument, we draw upon ethnographies undertaken in two clinics. The first study focuses on a sub-specialism in medical genetics, *dysmorphology*, drawing together diagnosis and genetic counselling in the assessment and analysis of babies, children, and families suspected of having a congenital problem (Featherstone et al., 2005; Latimer, 2013; Latimer et al., 2006). The second study is based on prenatal screening for Down's syndrome, a routine procedure in many countries across Europe and the US (Thomas, 2014b). Both studies examine interactions between medicine, bioscience, and the family, including biotechnologies and clinical processes on the one hand and family members, bodies, and selves on the other. The clinic is, then, the intermediary between these domains.

Here, we focus on how dysmorphology and Down syndrome screening are done at the everyday level, including how different clinical processes are conducted in interactions between patients, families, and practitioners. Additionally, we examine how cases/patients and interpretations of conditions or bodies are assembled in interaction. We show how these processes and practices accomplish the

relation between certain forms of being and societal values to (re)create the conditions of possibility for stigma and the exclusion of some forms of life rather than others. We also capture how this instantiates how bio-politics is accomplished at the 'capillaries' (Foucault, 1980). As Haraway (1991: 203) suggests:

'The power of biomedicine and biotechnology is constantly re-produced, or it would cease. This power is not a thing, fixed and permanent, embedded in plastic and ready to section for microscopic observation by the historian or critic. The cultural and material authority of biomedicine's productions of bodies and selves is more vulnerable, more dynamic, more elusive, and more powerful than that'.

The arguments of this article share similarities with earlier ethnographies in healthcare institutions concerning how practitioners and others accomplish medical work in daily interactions, practices, and routines (Bosk, 1992; Silverman, 1987). Our methodological approach corresponds with classic interactionist work on the clinic around the complex interactions between practitioners, parents, and children (Davis, 1982; Strong, 1979; Strong and Davis, 1976), particularly the significance of 'discourse' (Silverman, 1981, 1987) and ideas around family, responsibility, and disease/illness. However, we extend this vital work in several ways. First, we explore where, and when, medicine is explicitly engaged with genetics and reproductive technologies. Here, unlike earlier studies, we treat family, relatedness, conception, and birth as explicit subjects and objects of clinical processes and practices (see also Rapp, 2000; Rothman, 1986) to highlight how ideas around persons, kinships, and being human are constituted.

Second, we bring together Foucauldian concerns with bio-politics and other theoretical sensibilities - 'disposal' (Latimer, 1997; Berg, 1992), 'absence/presence', and 'motility' (Latimer, 2013; Munro, 1996) - to analyse how people or things are moved in different spaces of discourse to accomplish stabilities in power relations (Latour, 1991). Whilst we focus on the explicit as well as the implicit and taken-for-granted (Pink, 2012), we are as interested in moments of deviation and apparent

contradiction as we are in routines, repetitions, and what is 'normal' in the settings observed. Sociologies of everyday life usually press routines and repetitions as productive of social relations (Berger and Luckmann, 1966). In contrast, as well as routines and repetitions, we focus on moments and occasions in which practitioners consume, hold in play, dispose of, and shift between supposedly contradictory frames of meaning and values. Rather than these shifts and moves being seen simply as 'deviations' (Silverman 1993) from a norm, or as infractions through which people mark others as different (Goffman, 1963), we examine what we call 'shifts' in extension (Latimer, 2004; Munro, 1996; Strathern, 1991) as both 'topic' and 'resource' (Garfinkel, 1967) for how participants attach to, and detach from, specific ethical concerns and moral forms; that is, everyday practices of in/exclusion that dispose of particular forms of life and give shelter to others.

We begin by describing the theoretical foundations on which our arguments are grounded. In what follows, we outline our studies before exploring how in the dysmorphology clinic, the living child is given shelter but, simultaneously, future reproductions of such children are enacted negatively and to be avoided; this reproduces dominant Euro-American forms of personhood, circulating notions of agency, will, and calculation. With reference to Down's syndrome, we capture how the condition is made absent and constituted as a negative pregnancy outcome. The article has two major contributions. Firstly, it identifies in/exclusionary practices in the clinic and how particular ways of being in the world are threatened, denied, or effaced. Secondly, it reveals how attending to the micro, banal, and everyday life of the clinic reveals who or what is valued in modern healthcare institutions and the contemporary social world. In doing so, we recognise how everyday situations and power relations, always local and specific yet also complex and heterogeneous (Foucault, 1973), are important for considering how people and 'the social' get un/made in everyday life.

Theoretical and Methodological Concerns

The methodological tradition in which our studies are rooted draws together aspects of interactionism and ethnomethodology with post-structural interests in power

relations, allowing us to engage with a particular way of analysing the social. Despite drawing on several concepts, we analyse the mundane, familiar, and taken-for-granted 'micro' practices, routines, and rituals which reproduce order and values (Garfinkel, 1967; Goffman, 1959). This corresponds to how stabilities are re-accomplished not just through how matters are settled, but also through how they become 'unsettled' (Latimer, 2008).

Our work focuses largely on interactions between practitioners, patients, and families, revealing how the intricate politics of small rules and transgressions add up to ordinary yet powerful symbolic ceremonies in everyday life (Goffman, 1959). Analysing the extraordinariness of ordinariness reveals the subtle scaffolding of interaction and how people – as 'members' (Garfinkel, 1967) – make sense of their world and produce a local order through taken-for-granted practices and conduct. With Garfinkel (1967: 11), we understand the meaning being registered and the sense being made as 'indexical' to the situation; 'the demonstrable rationality of indexical expressions and indexical actions retains over the course of its managed production by members the character of ordinary, familiar, routinised practical circumstances'. The artful practices of everyday life, for Garfinkel, create a moral order, that is, how people organise the world and local order. This is vital for considering the moral order of clinical life and how practitioners, patients, and families produce and reproduce particular moral values not only around everyday interactions but also around certain bodies/future bodies which appears as 'natural' and 'real'.

We also explore the micro-physics of power in the clinic. Foucault (1980) argues that power is not concentrated in one space or possessed by one person but is localised and fragmented. Invisible yet potent in its effects, power is realised in its reach 'into the very grain of processes and everyday life' (1980: 39); it 'produces and traverses things, it induces pleasure, forms of knowledge, produces discourses' (1980: 119). In this article, we show how power works in the clinic, namely by examining how it facilitates, mobilises, and elicits the actions and conduct of those subjected to it. This is primarily achieved in discourse as described by Foucault, that is, in the culturally constructed language and practices of embodied individuals. Specifically, 'discourses' (Silverman 1987) are invoked, attached to, made

present/absent, and resisted in different moments through different means. This makes up the social as a complex and not necessarily coherent tapestry of relations.

In the clinic, we reveal how persons (and particularly practitioners) constitute persons/bodies and identities through 'dividing practices' (Foucault, 1983: 208) which create classifications, particularly those enacting a relationship between identity-work (parents, practitioners) and how people categorise the 'objects' and 'subjects' of their interactions such as 'foetus', 'baby', or 'child' (Silverman 1987). Here, we explore shifts in 'extension' (Latimer, 2004, 2013; Munro, 1996; Strathern, 1991). Specifically, we draw on post-structural sensibilities to expand interactionism through attention to how, when, and where participants attach to and detach from different materials, discourses, bodies, and technologies in ways that bring into presence, displace, or make absent different identities as well as different moral worlds. As such, we show how people find consistency and stability in categories of people/future people to help perform identities and create order, but in ways that enact the clinic as a site of inclusion and exclusion. This involves focusing not only on the accomplishment of medical routines but also on deviations. By crosschecking 'accounts' (Garfinkel, 1967) with observations of what happens in the clinic, we are able to look across 'situated occasions' over time in a process of comparative interpretation to identify both patterns and deviations (Silverman, 1993).

We interpret these deviations/shifts not as mistakes or 'breaches' (Garfinkel, 1967) but as instances of 'motility', referring to how people or things are moved not just via discourse, but via shifts in extension. We capture what people make present and absent, view as important and unimportant, and who or what they categorise as normal and abnormal, at different moments in the clinic. Motility essentially helps 're-accomplish socio-cultural relations of power' and brings concerns and attachments into view (Latimer, 2008). Analysing motility also allows us to explore relations enabling 'disposal' (Latimer, 1997). We understand disposal as the means by which persons engage in ordering work to help maintain order in the clinic, that is, how they place, displace, and replace certain persons, ideas, or things (Munro, 1996). Thus, we relate the concept of disposal to how people erect an understanding

of certain persons/future persons and how they can be transformed into an Other at different moments (Berg, 1992; Goffman, 1963).

Here, we identify the theoretical undercurrents informing our approach. By exploring the ordinary and banal, we show how social relations and practices are equally mundane and dynamic and how local matters are important for grasping the life of the clinic as a site of bio-politics (Rapp, 2000; Silverman, 1987). Our claims are not an attempt to synthesise the entire principles of ethnomethodology, post-structuralism, and interactionism. Rather, we draw on conceptual tools from each of these approaches, rather than fully subscribing to them, to make our claims. It is not, therefore, a total theoretical framework intent on integrating concepts which are, by all accounts, difficult to amalgamate. We believe that by bringing together these principles – alongside the tropes of motility, disposal, and absence/presence – we offer a novel contribution to the field.

We will now briefly introduce the two studies from which the current article is drawn. Both studies were carried out in the UK National Health Service (NHS) contexts; one in a regional genetics service (dysmorphology) and another in a regional obstetrics and foetal medicine service (Down's syndrome screening). As such, we argue that our findings will likely be translatable, despite local effects/variations, to other hospitals, an example being the universality of policy stipulations for Down's syndrome screening in NHS hospitals.

Study 1: Dysmorphology

The first study is an ethnography of dysmorphology and, more generally, the practices and processes of clinical genetics (Latimer, 2013). Dysmorphology experts define themselves as concerned with the study of abnormal *forms*. The focus is on identifying which 'troubles' at the clinic are clinically pathological and examining the effects of congenital abnormalities/anomalies at the genetic level. In this sense, dysmorphology is entangled with the (bio)'politics of reproduction' (Ginsburg and Rapp, 1991). At the same time, it helps to produce, and embed, the post-genomic science of development, shape, and form. Patients are mainly babies, children, and kin relations, particularly parents and grandparents. Dysmorphology diagnosis

works at the boundaries between genetic techno-science, discourses of 'normal' development, 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'. Classification therefore proceeds not in terms of diseases per se but in terms of syndromes which includes both pathological and non-pathological signs and features, especially how bodies, including faces, *look*. Some of the children presenting at the clinic have severe troubles: problems of growth, brain shape and form, hearts, kidneys, and reproductive organs causing problems with function, with an extremely poor prognosis in several cases. Pathology at the genetic level is productive of syndromes which are holistic - they work across systems - and are, in addition, something that both someone and a family *is*. Thus, diagnostic categories are complex and associated with chromosomal abnormalities and genetic mutations. However, for many syndromes, no mutation has yet been made visible at the molecular level. Even in a syndrome where the mutation at the genetic level has been made visible, the pathway from the mutation to clinical picture is still unclear. At the time of the study, there were over 3000 syndromes described in dysmorphology databases. The clinic observed is particularly focused on establishing whether the syndrome that a child and/or their family express, the phenotype, has a genetic base or genotype. Importantly, treatment and care are difficult to measure because geneticists do not treat patients. Rather, they diagnose and counsel them with regard to reproductive risks and diagnostic work itself is protracted and uncertain. In a sense, geneticists' practices concern the circulation and interpretation of information through which they attempt to, indirectly, *re-form* those families where they think there is risk of a genetic disorder being passed on.

Fieldwork was an intensive year-long observational study of a regional genetics service with different teams consisting of consultants of clinical genetics who were also clinical scientists, genetics specialist nurses, and associated clinical trainees. The study was carried out in November 2002-July 2003. Participant observation was triangulated with interviews with patients/families ($n=26$) and international experts in dysmorphology ($n=6$), and discourse analysis of health

policy, syndrome websites, geneticists' publications, and other public representations of their knowledge and practice. Participant observation was across all the different occasions and events that make up dysmorphology practice and process, including clinical consultations ($n=37$), local, national and international professional dysmorphology meetings ($n=6$), and home visits ($n=3$). Many of the subjects were children and their families, which necessitated full involvement, consideration and consent of parents to participate in the study. Despite the extremely sensitive focus of the research, no unexpected ethical problems were encountered.

In this article, only observations of the clinics are drawn upon. The clinics observed are small and in contrast to most other medical specialisms, consultations take about an hour and the diagnostic process occurs over a matter of years. Critically, there is often no diagnosis to be made and yet the diagnostic process runs alongside genetic counselling. That is, there is an assessment of risk over reproduction of children with the same kinds of pathologies and disabilities as those presenting at the clinic.

Study 2: Down's Syndrome Screening

The second study is an ethnography of screening for Down's syndrome in prenatal care (Thomas, 2014b, in press). Screening in the settings observed consists of parents receiving a 'risk factor', a numerical probability establishing the odds of a foetus having the condition. This categorises parents as 'lower-risk' or 'higher-risk'. In NHS hospitals and the settings observed, the recommended national cut-off level for this categorisation is 1:150 (a 1 in 150 'risk' of having a baby with Down's syndrome). If parents receive a risk factor above 1:150 (e.g. 1:300), they are 'lower-risk' and not offered diagnostic testing (amniocentesis or chorionic villus sampling/CVS). If they receive a risk factor below 1:150 (e.g. 1:50), they are 'higher-risk' and diagnostic testing can be arranged to prove or refute a suspected diagnosis. If parents decide against diagnostic testing, no further screening or testing for Down's syndrome is typically offered. If parents consent to testing and a diagnosis is established, counselling is offered by a practitioner before a decision must be made about

continuing or terminating a pregnancy. The main objective of screening is to identify women in whom a risk factor is deemed high enough to warrant offering diagnostic testing. Alongside prenatal measures designed to detect Down's syndrome are social support services for children with the condition, together with social movements and both autobiographical and media accounts on parenting a child with the condition (Thomas, 2014a, 2014b). The discourses of such outlets often portray living with the condition in positive terms and, essentially, as a situation one should not inevitably interpret as tragic or unwanted (Thomas, 2014a, 2014b).

Fieldwork took place at two healthcare institutions and included over 200 hours of observations of consultations and other medical work (office chat, cytogenetic laboratories, team meetings, etc.), interviews with 16 practitioners and 37 parents, and document analysis (pregnancy booklets, policy documents). Approximately one year (December 2011–December 2012, in clinic for once/twice a week) was spent observing each setting, paying attention to routines, deviations, discourses, practices of division, and accounts. The study primarily explored why the scientific and medical communities, together with parents, are so invested in the idea of prenatally detecting Down's syndrome. Only data collected via participant observation at one NHS hospital (i.e. its antenatal department) will be discussed here. The chaotic and complex department was occupied by midwives, doctors, consultants, maternity care assistants, and administrative staff along with patients.

Data for each study were analysed by exploring and dissecting the connections and disconnections, themes, deviations (Silverman, 1993), metaphors, and typifications in accounts and observations of the clinic. This tactic added rigour to our arguments so that we could make claims on strong grounds, and thicken descriptions as well as our interpretations. Ethical approval was granted by NHS and/or University research ethics committees for both studies. Further information on the methodology of each study is available elsewhere (Latimer, 2013; Thomas, 2014b).

Absence, Presence, Displacement: Down's Syndrome

We begin our analysis by capturing how persons or things are made absent or present in everyday practices. Here, we can see who/what is being marginalised and privileged. Investigating the presence of absence involves 'what is not said and who is not present in a localised context' (Pascale, 2011: 145). Absence has recently been a topic of consideration in STS literature (Rappert and Bauchspies, 2014) in terms of what is not constituted as a proper object for scientific investigation as well as what is done with the un/known. Thus, one aspect of absence we press here is what is *not* attended to in the production of biomedical knowledge and what is made invisible, silenced, or made to be so taken-for-granted that it falls outside of biomedical discourse.

To illustrate this point, we draw on the following extract from Thomas' project detailing a Down's syndrome screening consultation involving Nicola (midwife) and Mrs

Li (mother):

Nicola: I'm going to tell you about the screen and then I'm going to take you through so you can have your bloods done. You're offered the screening test today. It won't tell you if the baby has Down's syndrome but it provides a risk ratio which gives a lower-risk or higher-risk of the condition. If you're a higher-risk, we telephone you within three to five working days where you're invited back here. You'll receive counselling and you're offered a further diagnostic test called an amniocentesis. Have you heard of it?

Mrs Li: Yes. I had one in the last pregnancy. I'm going back to Cambodia in a few days' time for three weeks. What can we do? I'm back [date] when I'm having the [anomaly scan].

Nicola: The amniocentesis should take place in three and a half weeks because if you wanted to terminate, it's leaving it very late in the pregnancy. [Mrs Li looks concerned] If you came back as higher-risk, would you have an amniocentesis? Because if not, you might have to think whether having this test would be the best option. You could be higher-risk but it could all still be OK.

Mrs Li: I would rather know if I was higher-risk.

Nicola: OK. If you ring in six days' time, we might have your result. If you're higher-risk, we can book you an amniocentesis over the phone. But you should really

consider this because obviously the baby will be at such an advanced gestation for amniocentesis and potentially a termination.

Mrs Li: I understand.

Nicola: How old are you?

Mrs Li: Thirty-three.

Nicola: If you did want an amniocentesis, you would be counselled beforehand. It has a 1% risk of miscarriage and if there's a diagnosis, you're offered a termination of pregnancy. You could come back as lower-risk but lower-risk does not necessarily mean no risk [of having a child with Down's syndrome]. OK?

Mrs Li: OK.

This extract highlights many important issues: the figuring of mothers as 'lower-risk' or 'higher-risk'; the relationship between an increased maternal age and a diagnosis of Down's syndrome ('how old are you?'), and; the notion of nondirective care being difficult to uphold ('you might have to think whether having this test would be the best option'). Importantly, although Down's syndrome is cited, no further details on it are tendered by Nicola nor solicited by Mrs Li. In this consultation and many others, Down's syndrome is framed as a taken-for-granted category requiring no further explanation of symptoms, prognosis, and the social realities of the child who may have the condition. In addition, prior to screening, Nicola cites termination on three occasions, drawing on this as a resource to highlight the gravity of decision-making and how delaying this becomes increasingly problematic as a pregnancy progresses. However, the conjectural option of continuing a pregnancy following a diagnosis is never established. Thomas observed similar occasions in other screening consultations, including the condition being seldom addressed in explicit detail. At most, Down's syndrome is cited without any further clarification.

We argue that Down's syndrome is an example of absence in antenatal medicine. Attending to the everyday life of the clinic shows how the condition becomes a 'known' entity, with practitioners not providing, and parents not soliciting or questioning, details of it. Its absence acts as a stiff mould which masks the sizeable physiological and intellectual variation of people with the condition. It becomes widely constructed as a congenital condition effacing and despoiling

identity (Goffman, 1963), so much so that it has become absent as a topic worthy of further reflection in biomedical practice. It is in its familiarity as something 'abnormal' – as something one can terminate a pregnancy for – that it becomes invisible, thus masking an open and vital discussion regarding the complexity and variation of the condition. So whilst Down's syndrome screening is, as we will show later, problematically present as the topic of prenatal investigation, the condition as a diagnosis or as a state of being in the world is made absent.

Absence, Presence, Displacement: Dysmorphology

In this article, we illuminate something which is above and beyond absence/presence. Specifically, we find that at some moments in the clinic, certain things are made absent which are then given presence at other moments. It is this movement that accomplishes less explicit relations of ordering and accomplishes the bio-politics which affords the disposal and exclusion of some forms of life at the same time it reproduces biomedical power.

To explore this, we focus now on how babies and children as 'individual persons' are made absent and present in the dysmorphology clinic. 'Individual' personhood, for Euro-Americans, is figured in terms of the sovereign subject against which other kinds of 'being' are held as 'Other' (de Beauvoir, 2010 [1949]: 61). Figuring individual personhood is complex but involves notions of the discrete unbreached body together with notions of possession, will, and reason. What we find in the dysmorphology clinic are moments when, no matter how effaced and despoiled by a syndrome a child's body is, they can still be brought into presence as an individual person. This relates to the processes of objectification which constitute parent and practitioner relations. What is being objectified, rather than personified, are the bodies of babies, children and their relations – both the living child as well as future children. Thus, what is accomplished in the construction of these objectifications is not just the medicalisation of family and future reproduction but the association of family and reproduction with the ab/normality of the shape and form of bodies/minds as well as with diseases and problems with development and behaviour.

Here, we show how there is a shift between the objectifying practices that bring the body as an object into presence in the clinic, but which make personhood absent, and those practices that background the body to make the person present. This contradicts Young's (1997) work on how the body intrudes personhood into the clinic, despite all those practices that attempt to enact the mind-body split. Consider the case of Roger, around eight years old. The following extract is taken from a consultation in the paediatric outpatients department between the consultant geneticist (Dr Smith) and Roger and his family (mother, grandmother):

Dr Smith: I've reviewed his notes and I don't think there's anything [a diagnosis], we've established a few things.

Mother: I was so relieved when I got your letter [saying the condition has nothing to do with her kidney disease during pregnancy]. I blamed myself all these years.

Dr Smith: We can completely rule that out. There's some type of genetic problem likely to have occurred with him, there's nothing running through your family. We've looked for fragile X and chromosomes [...] [Roger] was really good [on the examination table]. I'm interested in movements because a new gene has been identified; these boys have learning difficulties and some funny movements. We're setting up this test in [place] and we could add Roger if you would like to go down that route. That's the only idea I have at the moment. I may have others in the future.

Like many parents in the study, Roger's mother blamed herself for his troubles but the geneticist exonerates her from blame and installs Roger's genes as the possible cause of his troubles. Whilst parents and family members are enrolled in the processes of objectification through which a child's troubles and its causes come into view, the effect of magnifying the gene and diminishing parental agency regularly occurs during consultations¹. In the clinic, what is being enacted is the purity of the clinical gaze (Foucault 1973) through practices that bring into presence the syndrome as located in the medical body, both the individual body of the child as well as the bodies of the biological family. Thus, in consultations with families and at local team meetings in the dysmorphology clinic, when practitioners present slides and discuss

cases, the living babies and children that formed the objects of dysmorphology are, at key moments, brought into presence as individual persons.

In another consultation with Roger and his family, Dr Smith discusses the use of Ritalin. The staff and family engage in processes through which Roger's hyperactivity is brought into presence as a key feature of his 'condition'. Amanda (specialist genetics nurse) states that his Ritalin will wear off soon, while Roger's mother and Dr Smith discuss how the Ritalin has changed his behaviour – pressing how things are 'much better'. Then two things happen. First, the grandmother raises the issue of how Roger still 'twitches'. Second, the mother reverts to pressing issues around his hyperactivity (problems getting Roger to sleep). It is at this moment that Roger's mother's concern – around managing his hyperactivity - gets displaced by Dr Smith. She does this by bringing Roger into presence as *a person* of a particular kind – a person with likes and dislikes ('he doesn't like to be on his own') and with a will ('he likes to have a grip on you'). By doing this, Dr Smith divides Roger's behaviour into those things that are to do with 'him', as a person (not wanting to go to bed, keeping a grip on his mother), from issues that are of clinical significance. Roger's mother, displaced by this redefinition of Roger's behaviour, acts as if her parenting skills have been called to account: 'I'm starting to limit how long I stay up there'. Dr Smith subsequently engages in repair work and reasserts that Roger keeping his mother up at night is not a clinical problem since it is something all children can do: 'I know it's difficult with all children, I know in my family it's not much different'.

In this shifting between absencing and presencing individual personhood, Dr Smith brings into presence her own humanity and sociality as well as that of Roger. At the same time, she asserts her authority as both a clinician, dividing the relevant from the irrelevant, on the one hand, and by displacing the mother's concern and disciplining her as a parent, on the other. Shifting between making personhood present, rather than the 'disease', is one way biomedical power is being accomplished. But it also exemplifies how the doctor shifts between making herself present as the proponent of the disciplined gaze, who can divide the pathological and abnormal from the normal, and a social being. But bringing a child into presence

as an individual person alongside giving the genetic agency for their bodily troubles also has the effect of giving the child 'shelter' (Latimer, 1999). Here, what we want to press is how the clinic, by bringing the child into presence as an individual person, includes them by giving them 'face' and 'place' (Latimer, 2013) in ways that mean that the clinic, society, parents, and family all have a moral and social responsibility to them. The next extract illustrates our claims:

David (8 year old boy with seizures, motor problems, and severe delay) leaves the clinic with his mother and father:

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.

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

Dr Smith goes on to define David as a 'classic Polymicrogyria': dribbling, gait, no speech, developmental problems, co-ordination problems, and epilepsy.

Throughout this encounter, Dr Smith brings David into presence as a person; he's unique, not as severe as other children she knows about, and will reach adulthood. While the doctors discuss the possibility that David's genes have caused his problems, they bring him back into presence as an individual person: 'sometimes you just get glimpses of what he could be like', '[h]e has a good understanding of how the world works and how to get people to do what he wants'. This means as the clinicians draw upon a notion that the child's condition is biologically determined

rather than socially or culturally constructed, they also hold to an idea that there is an essence to persons; that a child, despite abnormalities on the surface and in the depths of the body, is a person. As such, David is given shelter. He is included, restored momentarily as a subject to whom particular rights accrue.

However, an extraordinary feature of dysmorphology is that the diagnostic and humanitarian work of inclusion is done alongside genetic counselling. This means that at the same time as the living child is given shelter through bringing them into presence at moments as an individual person, the geneticisation of their troubles means parents, and their reproductive relations, become the site of intense risk. For example, in one extraordinarily swift move, Dr Smith also brings into presence the possibility that the family need to know whether they might reproduce another child like David, with the implicit understanding that a reproduction of another David is 'disposable' (Latimer, 1997; Munro, 2001): '[It would be useful for the daughter] and people like to know why.' That is, it would be useful for the daughter and other people to know whether there is a genetic problem with David because they can assess the risk of someone with his condition being reproduced. David is held on the grounds of the human by bringing him into presence as an individual person, one with needs and rights, yet what is also brought into presence is the possibility that another person like him might need to be prevented.

By tracking dysmorphology over time and across situated occasions, absences and presences (and thus inclusions and exclusions) could be traced and discrepancies could be identified. Earlier in the article, we defined this trend as motility, of how people or things are moved in different spaces of discourse and can be made important or unimportant, present or absent, at different moments. This achieves socio-cultural relations of power and enacts attachment to – and detachment from – specific ethical concerns and moral forms. In short, in the dysmorphology clinic, the everyday practices of inclusion and exclusion can 'dispose' of particular forms of life at the same time as they give shelter to others. Thus, future children constituting reproductions of a living dysmorphic child are, quickly and tacitly, configured as excludable and transformed into the Other in the everyday ordering work of the clinic.

Attachment, Motility, Disposal

We have revealed how in moments of motility, 'shifts' (Latimer, 1997) allow for sudden switches between conceptual relations embedded in narratives and discourses. Shifts produce moves which mean presence is, at critical moments, magnified or diminished. Here, we build on the notions of motility and disposal in our analysis by drawing on the ethnography of screening for Down's syndrome and how cases become categorised by practitioners.

Classificatory practices are crucial to the ongoing work of medicine, particularly in terms of classifying certain bodies/future bodies as either normal or abnormal. In prenatal medicine, Down's syndrome is very problematic for practitioners and parents. Although screening/testing (and thus termination) is offered for the condition, the prognosis of a foetus with Down's syndrome is highly uncertain. The foetus is often viable yet the inconsistency of the condition's manifestation and ambiguity around symptoms is a common feature. This presents a thorny dilemma for practitioners – namely those in the foetal medicine department where Thomas (2014b) spent time during fieldwork – who must provide information to parents and concurrently negotiate the tricky terrain of deciding which situations constitute legal grounds for a termination. He found that this involves disrupting the distinction between the foetus and baby. During a pregnancy, ultrasound scans often give rise to a foetus *becoming* a baby (particularly early on). Yet once a diagnosis of Down's syndrome is established or suspected, a baby is transformed, once again, into a foetus. This dehumanising discourse technical discourse is used to settle the uncertainty and complexity of Down's syndrome; the foetus is universally and narrowly framed as 'abnormal'. Together with its 'absence' in the early stages of antenatal care, Down's syndrome thus is enacted as a negative outcome.

To highlight this further, consider the following extract taken from a consultation with Dr Karman (consultant), Elena (midwife), and Mr/Mrs Holt (parents) whose baby has an abnormal aortic arch:

Dr Karman: So would you like a late amniocentesis?

Mrs Hunt: I plan not to because I want to concentrate on the heart side of things. And I've heard from a few of the people that if something was wrong, a number of other problems would have been detected by now.

Dr Karman: Not in all cases do all other problems show up in the scans or diagnostic tests. The heart is linked to other stuff but this may be the only sign. A heart defect will indicate abnormality in 5% of cases and the only way you can know whether there are any problems is by an amniocentesis. But the likelihood is that the baby's chromosomal development is normal. That's 95% likely [Dr Karman smiles. The Hunts smile back].

Elena: You should book an appoint to come here again so we can keep an eye on everything.

Dr Karman: Yes [the Hunts nod]. Can you bring baby into the department after he or she is born?

Mrs Hunt: Sure.

Mr Hunt: Of course.

Dr Karman: I'd like to add a photograph of him or her to the [cleft] board.

Elena: Yes. If something is wrong, it's good for parents to see a picture with the problem and see that there is still a baby here.

Dr Karman: Absolutely [smiles at Mr and Mrs Hunt].

Mrs Hunt: Yes it's nice to know that you're [slightly pauses].

Dr Karman: [Interrupting] It's nice to see the baby ahead of the problem.

Elena: Definitely.

Mrs Hunt: Definitely. It's nice to see that you're not on your own.

Once more, plenty is going on here, including the difficulties of offering non-directive care. For instance, Dr Karman's claim that 'other problems' may be hidden and that an amniocentesis is 'the only way' to establish an absence or presence of 'abnormality' may incite anxiety in the Hunts and influence them to make certain decisions. In addition, we note Dr Karman's preference for 'baby' over 'foetus' once a pregnancy is *compatible with life* rather than *incompatible with life*, that is, a condition which may not require a termination of pregnancy to be offered. This is a frequent occurrence in the clinic.

Dr Karman also asks Mr/Mrs Hunt - despite a specific problem not necessarily being diagnosed other than an abnormal aortic arch - if they would bring their new-born baby into the clinic so a photograph can be added to the 'cleft board', a large picture display of recently born babies with cleft lip/palate and other conditions. If 'something is wrong', Elena deduces, others in a similar situation will benefit from seeing 'that there is still a baby here', with Dr Karman claiming 'it's nice to see the baby ahead of the problem. Re-birthing the (normal) baby status once a problem occurs is of paramount importance in the clinic. The cleft board is crucial here, playing to a child's future of normality (Silverman 1987). As Francine (midwife) explains, it allows parents to see 'that their babies could be diagnosed with certain abnormalities but at the end of the day, they still look normal'. Such technologies reveal the importance of 'normality', as a perceived visual absence of abnormality, in constituting fetuses/babies.

Interestingly, no picture of a new-born baby with Down's syndrome adorned the cleft board, reflecting the absence of the condition in screening consultations. We suggest that such practices - the absence of Down's syndrome in consultations/the cleft board, and using the term 'foetus' over 'baby' when discussing a possible termination of pregnancy for the condition - permit the disposal, exclusion, and effacement of the condition in antenatal care. Silverman's (1987) analysis of how the child with Down's syndrome is 'socially constituted' in the clinic is comparable here. He examines how illness or wellness are discursively organised in consultations between professionals and parents, and how clinical versions of situations incorporate and transform parental formulations of their child. Specifically, children with Down's syndrome and cardiac defects are constituted as 'social objects' in which the (medical) concerns of parents are reconstructed by professionals as 'social' issues, thus enacting a non-intervention policy and avoiding surgical intervention on behalf of the child's condition (1987: 134). Silverman captures how communication techniques are not neutral devices but derive from powerful discourses in which the ground is prepared for children with Down's syndrome to be positioned in the *social* rather than *medical* realm. Treatment is not offered and, in turn, this allows for their 'disposal'.

Although Silverman (1981) discusses 'disposal', this corresponds to postponing further medical treatment (here, disposal can arguably be substituted for 'discharged'). We use the term to signify something different. In the case of Mr/Mrs Hunt, the viability of the foetus allows Dr Karman to make a move to re-normalise the baby. Since a chromosomal abnormality is unlikely, the baby status is retained and an invitation for submitting a photograph to be placed onto the cleft board is tendered. In contrast, when the foetus/baby has or is suspected of having Down's syndrome, the baby is transformed into a foetus. Such moves restore the local order, namely by settling the ambiguous category of Down's syndrome (as 'viable' but as something one screens, tests, and possibly terminates for) and reinforce the boundary between normal (babies) and abnormal (foetuses). In what follows, this allows for the disposal, both figurative and literal, of a foetus with the condition.

Discussion

Our focus in this article is on how medical work is organised and performed in everyday routines and how in/exclusion becomes enacted in such practices. Specifically, it has two major contributions. First, we identify the value of bringing together different conceptual tools (from interactionism, post-structuralism, and ethnomethodology) to analyse the mundane and ordinary routines deeply embedded in the fabric of medical work which reproduce certain power relations and cultural values. Although early interactionist work in the clinic (e.g. Davis, 1982; Silverman, 1987; Strong, 1979) demonstrates these features, we extend this by examining how the use of technology is implicated, and thus negotiated, in such interactions. The bio-politics of everyday life reveals how technologies, and policies concerning them, are translated and ethically-laden, ideas which are absent from this earlier research. In addition, our account is a more complex and nuanced analysis of the micro-physics of power. As identified, power relations - including in/exclusionary practices - are always local and specific yet also intricate and heterogeneous. A focus on power relations involves us drawing on motility to examine how practitioners shift backward and forward between distinct discursive forms. The notion of motility deserves greater attention in sociology, and

particularly in analysing the everyday life of the clinic and beyond. In promoting its use, we hope to advance the theoretical understanding of the sociologies of everyday life and recognise the value of analysing the hidden and ordinary which, although establishing routines, are rarely straightforward (Pink, 2012).

We similarly place everyday life at the centre of our analysis, drawing on cutting-edge ethnographies to show the accounts, interactions, practices, affects, ambivalences, and, in/exclusions which surface when studying the everyday. In doing so, we press that ethnographic endeavours allow us to interrogate the dynamics of everyday life and capture its concreteness and intricacy (Pink, 2012). By analysing the micro and banal, we show how the familiar constitutes, and is constitutive of, the complexities, processes, and interactions of the clinic. What is more, as well as showing the importance of absence/presence and motility, we extend the concept of disposal which, hitherto, has yet to receive the attention it deserves. Silverman (1987) discusses disposal in relation to how children with Down's syndrome are not given a medical future but this does not go beyond the clinic walls. Here, we capture what is implicit and outside (as well as inside) the clinic, that is, the wider disposal and exclusion of certain (abnormal) bodies.

Second, the article identifies how values around bodies/future bodies intersect with clinical work and reproductive technologies in everyday practices. Agreeing with Silverman (1987) that ideas around medicine and kinship are discursively constituted in consultations, we show how babies/future babies are figured in ways which allow for their possible absence or presence, and thus inclusion or exclusion. Taken together, our studies address the complex interplay of practices and discourses in deconstructing both dysmorphology and Down's syndrome. In short, in showing how medicine is re-accomplished in ritual and mundane forms, we recognise how the everyday life of the clinic has transformed reproductive medicine, shaped the (bio)politics of reproduction (Ginsburg and Rapp, 1991), and re-enacted certain body-society relations. Our soft data asks hard questions about some of the most profound dilemmas of our time, specifically how the clinic is productive and reproductive of ideas around persons, kinships, and being human.

Our intention here is not to propose specific policies or discourses designed to change or improve practice. More modestly, we hope that by analysing the everyday and by theorising the mundane, this article will ignite reflexive, ethical, and pluralistic dialogues – and so better communication between practitioners, parents, and the wider lay public – around reproductive technologies and medical conditions. Reproductive technologies undoubtedly change the way we think and act and alter our perceptions of self, other, and what is ab/normal. Spilling beyond the biological and into public arenas and intimate lives, they are a potent site for uncovering assumptions buried deep in medical work and for exploring how ideas around family, parenthood, and personhood are enacted. By analysing the ‘terrible ordinariness’ (Bosk, 1992) of clinical life, we can highlight vital questions for practitioners, parents, governments, and sociologists alike around what lives we consider valuable and ‘normal’ as a society.

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Notes

1. Many families engage in the surveillance, assessment, and evaluation of their family relations with respect to the new genetics (Featherstone et al. 2006).

References

Bauman Z (1990) Effacing the face: On the social management of moral proximity. *Theory, Culture & Society* 7(1): 5-38.

Berg M (1992) The construction of medical disposals: Medical sociology and medical problem solving in clinical practice. *Sociology of Health and Illness* 14(2): 151-180.

Berger PL and Luckmann T (1967) *The Social Construction of Reality: A Treatise in the Sociology of Knowledge*. New York: Anchor Books.

Bosk CL (1992) *All God's Mistakes: Genetic Counseling in a Pediatric Hospital*. Chicago: University of Chicago Press.

Davis AG (1982) *Children in Clinics: A Sociological Analysis of Medical Work with Children*. London: Tavistock Publications.

De Beauvoir S (2010 [1949]) *The Second Sex*. London: Vintage.

Featherstone K, Atkinson P, Bharadwaj A and Clarke A (2006) *Risky Relations: Family, Kinship and the New Genetics*. London: Bloomsbury Academic.

Featherstone K, Latimer J, Atkinson P, Pilz DT and Clarke A (2005) Dymorphology and the spectacle of the clinic. *Sociology of Health and Illness* 27(5): 551-574.

Foucault M (1973) *The Birth of the Clinic: An Archaeology of Medical Perception*. London: Tavistock Publications.

Foucault M (1980) *Power/Knowledge*. New York: Pantheon.

Foucault M (1983) The subject and power. In: Dreyfus HL and Rabinow P (eds) *Michael Foucault: Beyond Structuralism and Hermeneutics*. Chicago: University of Chicago Press, 208–226.

Garfinkel H (1967) *Studies in Ethnomethodology*. Englewood Cliffs, NJ: Prentice-Hall.

Ginsburg FD and Rapp R (1991) The politics of reproduction. *Annual Review of Anthropology* 20: 311–343.

Goffman E (1959) *The Presentation of Self in Everyday Life*. London: Allen Lane.

Goffman E (1963) *Stigma: Notes on the Management of Spoiled Identity*. New York: Simon and Schuster.

Haraway D (1991) *Simians, Cyborgs and Women: The Reinvention of Nature*. New York: Routledge.

Latimer JE (1997) Giving patients a future: The constituting of classes in an acute medical unit. *Sociology of Health and Illness* 19(2): 160–185.

Latimer JE (1999) The dark at the bottom of the stairs: Participation and performance of older people in hospital. *Medical Anthropology Quarterly* 13(2): 186–213.

Latimer JE (2004) Commanding materials: (Re)legitimizing authority in the context of multi-disciplinary work. *Sociology* 38(4): 757–775.

Latimer JE (2008) Creating text, analysing text: A note on ethnography, writing and power. *Cardiff University School of Social Sciences Working Paper*, No. 106.

Latimer JE (2013) *The Gene, the Clinic and the Family: Diagnosing Dysmorphology, Reviving Medical Dominance*. London: Routledge.

Latimer JE, Featherstone K, Atkinson P, Clarke A, Pilz DT and Shaw A (2006) Rebirthing the clinic: the interaction of clinical judgement and genetic technology in the production of medical science. *Science, Technology and Human Values* 31(5): 599–630.

Latour B (1991) Technology is society made durable. In: Law J (ed) *A Sociology of Monsters: Essays on Power, Technology and Domination*. London: Routledge, 103–131.

Munro R (1996) The consumption view of self: extension, exchange and identity. *The Sociological Review* 44(S1): 248–273.

Munro R (2001) Disposal of the body: Upending postmodernism. *Ephemera* 1(2): 108–130.

Pascale CM (2011) *Cartographies of Knowledge: Exploring Qualitative Epistemologies*. London: Sage.

Pink S (2012) *Situating Everyday Life: Practices and Places*. London: Sage.

Rapp R (2000) *Testing Women, Testing the Fetus: The Social Impact of Amniocentesis in America*. London: Routledge.

Rappert B and Bauchspies WK (2014) Introducing absence. *Social Epistemology: A Journal of Knowledge, Culture and Policy* 28(1): 1–3.

Rothman BK (1986) *The Tentative Pregnancy: Amniocentesis and the Sexual Politics of Motherhood*. London: Pandora.

Silverman D (1981) The child as social object: Down's syndrome children in a paediatric cardiology clinic. *Sociology of Health and Illness* 3(3): 254–274.

Silverman D (1987) *Communication and Medical Practice: Social Relations in the Clinic*. London: Sage.

Silverman D (1993) *Interpreting Qualitative Data: Methods for Analysing Talk, Text and Interaction*. London: Sage.

Strathern M (1991) *Partial Connections*. Maryland: Rowman and Littlefield.

Strong P (1979) *The Ceremonial Order of the Clinic: Parents, Doctors and Medical Bureaucracies*. Henley-On-Thames: Routledge and Kegan Paul.

Strong P and Davis AG (1976) Aren't children wonderful? The allocation of identity in developmental assessment. In: Stacey M (ed) *The Sociology of the NHS, Sociological Review Monograph 22*. Keele: University of Keele, 156–175.

Thomas GM (2014a) Cooling the mother out: Revisiting and revising Goffman's account. *Symbolic Interaction* 37(2): 283–299.

Thomas GM (2014b) *The Everyday Work of Healthcare Professionals: An Ethnography of Screening for Down's Syndrome in UK Antenatal Care*. Unpublished Doctoral Thesis, Cardiff University, Cardiff.

Thomas GM (in press) An elephant in the consultation room?: Configuring Down syndrome in UK antenatal care. *Medical Anthropology Quarterly*.

Young K (1997) *Presence in the Flesh: The Body in Medicine*. Cambridge: Harvard University Press.

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