

DRAFT PAPER

The moral and sentimental work of the clinic: the case of genetic syndromes

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Abstract

This paper reports on the genetics clinic and examines the wider functions it provides for parents who have a child with learning disabilities that may be associated with an underlying genetic cause. It derives from an ethnographic study of one clinical genetics team within a UK clinical genetics service and their clinical caseload, specifically their cases of genetic syndromes associated with dysmorphology, a speciality within clinical genetics. Dysmorphology is the medical study of abnormal forms in the human and is concerned with the identification and classification of a variety of congenital malformations. Our analysis of the clinical consultations and subsequent interviews with parents indicate that obtaining a genetic diagnosis and classification of their child's problems was not the sole function of these consultations. In addition, the clinic provides parents with moral absolution from having 'caused' their child's problems and is an important site for the sentimental and celebratory focus on the child. Thus, the role of the clinical genetics service is not merely to assemble a diagnosis from the available information and to provide a source of expert opinion on the causes of the condition, but to provide reassurance to parents who might otherwise blame themselves (or be blamed by others) for their child's condition. An important aspect of these consultations was the sentimental work of repairing the child, providing a sphere in which the development and behaviour of the child is discussed in favourable terms, and given assurances of 'normal' parenting and family life, often in marked contrast to their experience in the wider public world. Thus, the work of establishing diagnostic categories also allows important moral and sentimental work to be accomplished within the clinic.

The moral and sentimental work of the clinic: the case of genetic syndromes

Introduction

The development of genetic technologies in the field of medicine has given rise to a substantial body of research that has examined the resultant clinical services, in particular the work of genetic counselling. The scope of this paper does not permit a comprehensive review of this work (for overviews of the literature see Evers-Kiebooms and van Den Berghe, 1979; Biesecker, 2001; Pilnick & Dingwall, 2001; Wang et al., 2004.), however, areas of interest have understandably included the process outcomes of counselling: recall of information, patient satisfaction, predictive testing decisions and reproductive choices following counselling (Black, 1980; Somer et al., 1988; Shiloh et al., 1990; Michie et al., 1994; Michie et al., 1996; Michie et al., 1997; van Zuuren et al., 1997; Veach et al., 1999; Bernhardt et al., 2000; Collins et al., 2001; Starke & Moller, 2002; Barr & Millar, 2003). Recently, there has been increased emphasis on the psychological dimensions of the clinical encounter (see for example, Kessler, 1992; McConkie-Rosell and Sullivan, 1999), the extent to which the principle of non-directive counselling is achieved (Kessler, 1997; Elwyn et al. 2000) and the experience of counselling from the patient perspective (Green & Murton, 1996; Hallowell & Murton, 1998; Veach et al. 1999; Collins et al., 2001; Skirton, 2001).

More widely, the experience of parents who have a child with a disability has been a focus for research since the early 1970s (Brett, 2002). The scope of this paper precludes a comprehensive review of the literature. Instead, we concentrate on one area where there are relevant parallels with our own work. A substantial contribution to the literature examining children with a disability has as its focus the extent to which they are stigmatised. Studies have examined the experiences of parental perceptions of stigma for a range of conditions. Some focus on what Goffman (1963) terms 'discredited' individuals where difference can be identified through their appearance. These include conditions such as craniofacial disorders (Hanus et al, 1981), Down Syndrome (van Riper et al, 1992; Prussing et al, 2005) and obesity in children, which although not a disability as such is nonetheless a stigmatised condition (Latner and Stunkard, 2003). Additionally, there are a number of studies examining families with 'discreditable' (Goffman, 1963) members, where behavioural characteristics, although not immediately apparent, are stigmatized, such as developmental coordination disorders (Segal et al, 2002) and epilepsy (Carlton-Ford et al, 1997). Studies have also examined parental coping mechanisms for 'courtesy stigma', a notion discussed by Goffman (1963), which an individual can acquire as a result of a family relationship with a stigmatized individual, thus causing them to be disvalued by association (for example, Birenbaum, 1992; Gray, 2002; Norvilitis et al, 2002; Green, 2003; Mckeever and Miller, 2004). This latter body of work is particularly salient in the light of our findings about parental perceptions of

stigma and the sentimental work performed in the genetics clinic reported below.

Dysmorphology

Dysmorphology refers to the professional discipline of delineating disorders affecting the physical development of the individual, before or after birth, and includes the recognition of specific patterns of physical features in patients with a range of problems (Aase 1990). This specialism has been described as 'the study of disordered development' (Harper, 1998:83) and includes the recognition of specific patterns of physical features and contingent problems that include underlying abnormalities of systems. These features may be associated with abnormalities but may not be abnormal in themselves. However, particular patterns of physical features have come to be associated with underlying systems abnormalities such as heart defects, or delayed intellectual development. When patterns of malformations are deemed to have reached a level of regularity across different cases and are thought to arise from a single underlying pathogenetic mechanism, they are named as a syndrome. There are several thousand named syndromes currently held within international clinical databases and textbooks (Jones, 1997). Patients are mainly babies, children, teenagers, and young adults.

The majority of syndromes are associated with a genetic basis, which are categorised as single gene defects or chromosomal disorders. Chromosomal disorders occur spontaneously and are referred to as having occurred *de novo* and where this is believed to be the cause of the condition, the risk of recurrence within the family is assessed as being low, particularly where no abnormality is present in a parent (Harper, 1998). However, some syndromes are inherited familial conditions and if this is the case, then the clinic can provide families with the likely risk of recurrence in future pregnancies.

Dysmorphia in children clearly throws into relief the topic of identity-work within the clinical genetics setting. Dysmorphia gives rise to actual or potential threats to the attributed identity of the child, through the implications of spoiled appearance (Goffman 1963). In addition, because it is implicated in *genetic* medicine, this creates the potential for moral threats to the parents' identities and it is to this subject that we now turn.

We draw upon data from a one-year ethnographic study of the process of the clinic. Observations of family and clinician interactions within specialist clinics and subsequent interviews with a sub-set of parents and (where possible) patients have been carried out to examine their experiences of attending the clinic and the process of diagnosis more widely. The result is a marriage of two sets of data, the observed, and the reported, experience.

Methods

Within this ethnographic study, one clinical genetics team and their patient population were followed over a period of 9 months, from November 2002 to

July 2003. Consultations (n=37) were observed within clinics (n=12) based in three local hospitals. Although the caseload of the clinical team was not dedicated to dysmorphology cases, a large number of their referrals (32) involved dysmorphology. The average length of time allocated to each consultation was one hour and this generated 44 hours of observation, yielding notes that included near-verbatim text. We also observed local professional dysmorphology meetings (n= 6) where cases were presented and discussed. In addition, a large number of less formal encounters between professionals was observed. During this period of observation, 16 patients and their parents agreed to be interviewed to explore the consequences of these diagnostic processes and their experiences of the genetics service. In total 26 people were interviewed. These referrals represent a range of stages in the diagnostic process.

Results

Some parents received a diagnosis of a named syndrome associated with their child's condition relatively quickly once they had been referred to the clinical genetics service. However, for the majority, the process of attendance at the clinic and the search for a diagnosis continued over a number of years. In addition, referral did not always result in an unequivocal diagnosis of a named syndrome, and in such cases, parents were usually provided with a number of potential syndromes that may be the cause of their child's disabilities, provided with the likely aetiology and the risk of recurrence.

The moral work of the clinic

The clinic provides a confessional space where parental concerns about the aetiology of their child's condition can be discussed and where the clinical team can absolve parental feelings of blame and responsibility for having 'caused' their child's condition in some way.

Blame and responsibility

The process of referral to the clinic involves the clinical team scrutinising not only the patient, but also their parents and wider family members for clues that may help them to identify the cause of the child's disabilities (for further elaboration see Featherstone et al 2005). For many parents, their referral to the genetics clinic, and its association with inherited 'familial' conditions meant that they scrutinised other family members for an associated disorder. For example, this mother recounts her child's referral to a London specialist who asked whether they had been referred to the local genetics service. The mother recalls her alarm and anxiety at the suggestion that the condition might have a genetic basis. Discovering that 'genetics' could be involved provoked the fear that she or her husband had caused their child's problems through the combination of their genes:

I mean if someone's got a genetics problem it's hereditary and it is something that Ross [husband] and I had done together and it was obviously very, very scary.

[INT 10: diagnosis of *de novo* mutation]

Because a genetic diagnosis has the potential to identify the origins of the condition the clinic also provides the opportunity to attribute blame and responsibility for transmission. The genetic nature of the referral often led to parental (and wider familial) concerns that they must have contributed in some way, particularly through an act or omission during the pregnancy that had 'caused' or allowed this genetic change to occur. For example, this mother recounts how she has continually blamed herself for her child's condition. She has considered an array of potential events, lifestyle choices, and other incidents that she believes may have contributed to or caused her son's condition. She reviews a large number of factors: occasional alcohol consumption, medication, diet and a holiday flight during her pregnancy that she speculates may have been contributing factors:

Mum: I think as a mother you constantly blame yourself. I blame myself what I done in pregnancy although I've never smoked in my entire life, I don't drink, I have the occasional glass of wine [...] it was lots of things, you know, I'd think: 'Oh gosh, did I take paracetamol for headaches', and lots of things like that, you know. 'Was it flying, going to our cruise?' **[INT7: Condition?]**

As with the work of the clinical team (Featherstone et al, 2005) parental surveillance also extended to the wider family. Parents reported examining their family history and other family members for similar problems that might indicate the familial origins of their child's condition or spectrum of problems. For some parents, the identification of a genetic cause for their child's condition enabled them to attach these feelings of blame to a specific family member, usually a parent, grandparent or a 'side' of the family. In the example below, the consultant provided this couple with a diagnosis [polymicrogyria] for their son's condition and reassures them that although it is a genetic condition, it is not familial and thus the chance of recurrence in future pregnancies is 'low'. However, this does not provide these parents with complete reassurance; they find it hard to believe this condition could have been a random event; and this woman focuses on her husband's 'side' of the family. She also describes how she continually questions whether she had caused her child's condition in some way:

Mum: is it genetic?

D: yes but so far, we don't think it runs in families. A gene is involved and early in the development

[...]

Dad: its funny its come from nowhere

D: which part of the family were you worried about?

Mum: his side, his mother and his sisters children, we've not asked them about it, its difficult

[they discuss the risk of this condition affecting future pregnancies and the diagnosis]

A: do you feel all your questions have been answered

Mum: the why question is always in my mind, having had the baby, did I do anything?

[t Swansea 7th feb 03]

Parents also reported that the attribution of blame and responsibility was also directed at them from other family members, usually grandparents, who blamed their daughter- or son-in-law for causing or passing on the condition in some way. Most commonly, mothers recounted stories both within the clinical setting and during interviews at home, of being identified as the likely source of their child's problems, either by passing on a familial problem or through acts or omissions during the pregnancy itself.

Parents also reported that such comments were not restricted to family members, but that their wider circle of friends and acquaintances had also suggested that they were in some way responsible for their child's problems; one mother recalls being asked directly by an acquaintance 'What did you do?' Similarly, this extended in some cases to professionals involved in the care of the child, such as teachers and health visitors, who questioned their parenting skills. As one mother whose child had been diagnosed with a syndrome that caused poor weight gain, described it: 'They [health visitors] accused me of taking food away from her.'

Although most commonly mothers suggested that they were responsible for their child's problems, there were instances where fathers sought reassurance from the clinical team, often volunteering specific events or behaviour in their past that they felt could be responsible. One father was concerned that environmental factors and aspects of his lifestyle in the past may have caused his child's condition. He had worked in a nuclear power station and '*took drugs*'. His son had recently been diagnosed with polymicrogyria and the consultant reassured him that these factors were unlikely to be associated with the condition; clarifying the distinction that although his son had a genetic condition, it was not necessarily an inherited, familial condition.

Thus, a wide range of both internal and external pressures contributed to these parents' feelings of guilt and the subsequent intense scrutiny they carried out of their behaviour to identify the cause of their child's condition. The genetic nature of the referral itself often started these feelings of guilt, but it also added to their belief that 'it must have come from somewhere'. Parents, in particular mothers, expressed their own internal feelings of blame and guilt, which were exacerbated by the views of family members and wider social contacts.

Absolving parents from blame

The clinical team routinely reassured parents who attended the genetics service that they were not to blame for their child's condition, and this was achieved in a number of ways. If the condition was identified as a *de novo* (spontaneous) mutation, then parents were reassured that they had not transmitted the condition to their child or caused it in some way through their lifestyle choices and behaviour. In those cases where the condition was a familial inherited condition, parents were also reassured that they were not to

blame because they had no prior knowledge of their risk of transmitting this condition to their child and also it presented only a risk of transmission, it was not an inevitability. For example, this mother expresses her relief at her son's diagnosis. Even though the clinical team have been unable to diagnose a specific syndrome, they rule out a familial cause for the condition and this appears to alleviate her anxieties that she may be to blame:

D: looking at a purely neurological point of view I can't see anything that's a problem

[A takes child to the playroom]

D: I've reviewed his notes and I don't think there's anything, we've established a few things

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

D: 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...[A]: 15th of January 2003]

However, such explanations of the aetiology of these syndromes do not mean that parental feelings of blame and responsibility disappeared from their discourse. Parents still appeared to be searching for the reason it happened to them and to identify their role in causing their child's condition. In response to this, the clinic provided parents with high levels of reassurance in a number of ways.

The Clinic as a Site of Reassurance

The clinic functions as a site of reassurance for both parents and the clinical team. The pursuit of a genetic diagnosis provided parents with an extended time with an 'expert' on their child's condition, the child's development was monitored and assessed over an extended period during which a number of investigations are carried out, usually over a number of years. In turn, parents often reassured the clinical team about the benefits of attending the clinic, the development of the child and their ability to cope with their child's disabilities.

Monitoring and assessment

Parents often spoke of valuing the long-term support the clinic provided. Parents received this support and reassurance over an extended period - often years- during which the families attended the clinic, ostensibly in the pursuit of a diagnosis. Each consultation routinely included a detailed physical examination of the child by the same consultant and this typically involved a close examination of the child's body. These examinations were explicitly compared with, and judged against, previous assessments of the child's development and this is often an important source of reassurance for parents.

In this example, although the consultant states that she is unsure whether she will be able to provide a definitive diagnosis of a named syndrome for their child, she can and does provide reassurance. The child's problems appear to

be stable and are not deteriorating; she implies that this is good news for her long-term prognosis.

D: I'll also suggest some basic blood tests, though unlikely to be changes in the overall metabolism. We may or may not get an answer [...] The important thing is her problems are static, they aren't getting worse [...] This is in her favour [...] any other questions?

Dad: I'm pleased it's static, we're dealing with what we've got.

[NM 22nd of January 2003]

The severity of the child's condition was often explicitly placed within the scale and severity of problems associated with the specific condition or syndrome. The consultant is a specialist in the field who is likely to have seen a similar case or diagnosed this rare syndrome before. The clinical team often reassured parents that their child had a mild form of the syndrome or was developing better than expected. This is an example of clinicians displaying their expertise; because they have seen a number of children with this rare condition, only they are able to comment on the likely extent of their future development. In the following extract, the clinician states that although the child's development is likely to be adversely affected by the syndrome, the extent of his developmental problems cannot be established through an MRI scan of his brain. However, she does add reassuringly that his development has been better than she would expect to see in children with this condition, explicitly listing his abilities and comparing him to other children she has seen with this syndrome.

D: well lots of seizures can impair development whatever his learning potential is. Its difficult to know, we can't really judge that from his MRI his is milder than other forms of pachyria he's already doing more that I'd expect, sitting up, babbling, looking at the book [...] He's milder, he's lovely, he's interactive and a lovely boy, so it might be in his case intensive input could make a difference. I've seen a lot of children who I couldn't recommend. **[HD: 20th jan 2003]**

Mutual reassurance

The clinic is also a site for mutual reassurance. As well as receiving reassurance during clinical consultations, parents often reassured the clinical team about the benefits of attending the clinic, the development of their child and their ability to cope with their child's disabilities. For example, in this extract, during the initial taking of a history by the consultant, this mother reassures her that in general her child is doing well despite the underlying discussion of the severe abnormalities and associated health problems this child has.

D: so really her development is fine?

Mum: yes.

[discussion of specific ear and feeding problems]

D: any other comments about her health generally?

Mum: she's doing really well.

[NM 28th may 2003]

Parents also provided reassurance not only that they were coping with their child's disabilities but also that their child was a vitally important part of their family and made a significant contribution to family life. For example, this mother makes it clear to the team that despite his severe developmental delay she has no concerns or worries about her son. She describes his ability to communicate with them, his sociability, the fact he has many friends and has a good relationship with his sister. She concludes by saying:

Mum: ...we were talking about other things this morning, he's a lovely child, he's happy and healthy. Its got to the point when we'd like to know what's caused it. Some people are more intelligent than others. I'll be happy if he's happy, if he gets a little job or stays with us for the rest of his life.

[23rd April 2003 Carmarthen clinic]

Parents provided this reassurance not only about the development and progress their child was making, but also in terms of the benefits they felt from attendance at the clinic itself, even where a diagnosis has not been made. During his clinical appointment one father said:

Dad: don't think that by finding no syndrome it's a problem, I see lots of kids where when you ask the parents and they don't know, but at least you've worked out that he hasn't got a lot of things that were worrying us. [B 19th feb 2003]

The sentimental repair work of the clinic

An important aspect of these clinical consultations was the work of repairing the perceptions of identity of the child and the family. Attendance at the clinic meant that parents were in an environment where their child was routinely admired by the clinical team, rather than treated as a source of shame and stigma. This is in marked contrast to these families' experiences in the wider community. Several families reported a wide range of negative reactions to their child that they found upsetting and stigmatising.

One mother reported that she had found adults staring at her child when she took him swimming because of the growth on his back, which was not visible when he was clothed. In another, poignant account, the parents of a child with *cri du chat* syndrome, the wailing of the baby, which is characteristic of the condition, and hence gives the syndrome its name, meant that they were unable to "hide" her condition. They felt that people in their local community crossed the road rather than meet them when they were out with their child.

A focus on the positive

The children who attend this clinic often had dysmorphic features of varying severity, some of which relate to the face or head. Although these features may be considered 'abnormal' in themselves, for example, craniostenosis [an enlargement of the skull], such features can also be extremely attractive, for

example, children with abnormally large eyes [which may be a feature of ...syndrome] or elfin features [which may be a feature of ...syndrome]. However, irrespective of the apparent severity of their dysmorphic features, all these children were described in similarly sentimental terms. [KF to do]

During the initial physical examination of the child, where physical abnormalities associated with an underlying syndrome are explicitly being sought, the consultant discussed their physical features and although this was in the context of identifying a dysmorphic condition, they routinely described the child in terms of their physical attractiveness. For example, a young boy with suspected Russell Silver syndrome is 'gorgeous' and a 'little charmer'; a little girl with cardiomyopathy is a 'gorgeous little girl', and a child with 22Q is 'very sweet'. The clinical team often explicitly described the child's features to parents in a positive way, using adjectives such as 'pretty', 'handsome' and 'gorgeous'.

This extended to the examinations of what were in some cases, children with severe physical abnormalities. In this example below, this young child has Goldenhar syndrome [hemifacial microsomia], his features are clearly asymmetric, he has dysplastic ears [low and set back], large auricular tags, Epibulbar dermoid [ophthalmology problems], an asymmetric face, mild facial weakness on his right side and Hemivertebrae. The consultant concludes her examination by declaring that he is 'gorgeous'. She appears to play down the severity of his abnormalities even in the face of parental insistence that his physical malformations are severe:

D: his asymmetry is not that marked

Mum: the position of his ears is quite different

D: [she holds his head in her hands] you don't look too bad at all, in fact gorgeous!

[T Swansea 7th feb 03]

The work of normalising the families and children

The clinical team also carried out the repair work of normalising these families within the consultations. A wide range of behavioural characteristics displayed by children likely to be interpreted in other formal settings as problematic or disruptive were actively accepted and enjoyed within the clinic. This was often in contrast to these families' experiences in the wider community, as they commonly reported within the interviews. For example, obstructive or noisy behaviour disrupting the clinic was never commented on as a problem to be managed, or that the child should be controlled or restrained by the parents. Instead responses to such behaviour were universally positive, with these children described as 'mischievous' and 'lively' and to be enjoyed and the team reinforced such behaviour as important signs of being a 'normal' child.

For example, during one consultation the little boy was extremely disruptive and noisy, shouting, emptying a large metal waste bin, repeatedly trying to

open the door and leave, opening cupboards and riding his tricycle round the room. The clinical team only intervened when there were concerns about his safety. During this relaxed and friendly consultation, his behaviour was celebrated and actively enjoyed by the team.

The clinical team used a number of devices to achieve this repair work. They commonly compared the child's behaviour to that experienced by 'normal' families, the clinicians own family or by commenting on the universal nature of problems faced by parents. In the case below, the consultant reassures this mother that some of their child's behavioural problems are 'normal', adding that there are similar problems with the children in her family.

Mum: getting to sleep is a problem [she describes how difficult it is to get him to 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].

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

Mum: I'm starting to limit how long I stay up there.

D: I know its difficult with all children, I know in my family it's not much different....

[A]: 15th of January 2003]

Despite often-severe developmental delay, or abnormalities being present, the clinical team often explicitly grouped these children with other 'normal' children, emphasizing their sameness. In one consultation, in the face of pressure from other professionals, in this case teachers at his nursery, who have suggested that the child's dribbling is abnormally severe, the specialist nurse reassured these anxious parents that this was within normal levels. As a former home visitor, he had seen many children with similar levels of dribbling, and suggested a simple treatment for the rash this causes.

Being good parents

The clinical team routinely reassured parents that they were doing the best for their child and praised them for being 'good parents'. Here, the clinical team see a 4 year-old with severe developmental delay. He has been attending the clinic for a number of years and although a large number of investigations have been carried out, there is no diagnosis. He is attending the clinic because there is a suggestion that he may have Noonan's syndrome. The consultant paediatrician attending the consultation adds that he is 'a lovely little boy' and praises the parents for their child's lack of behavioural problems often associated with his spectrum of problems:

[the consultant takes a history and both parents are reassuring that he is generally a contented and happy child, they all agree]

W: he's one of these unusual children with developmental problems but no behavioural problems, that I suspect is a testament to you [addressed to mother].

[19th feb 03]

The clinical team also explicitly acknowledged that the parents were the 'experts' who were best placed to judge their child's needs. They encouraged a child-focussed and commonsense approach to caring for these children, emphasising that the parents had the day-to-day experience of looking after their child.

Discussion

Although the work of assembling a diagnosis is an important function of the clinic (Featherstone et al, 2005), other work is carried out within this setting that appears to have a significant function for families. Within this paper we argue that rather than the inability to provide parents with a definitive diagnosis resulting in a potential 'failure' of the clinic, the lengthy process of attending the clinic over a number of years in the search for a diagnosis, in itself, appears to provide parents with a number of benefits. An important function of the clinic is the moral and sentimental work it carries out, which is illustrated by the findings we discuss above.

The moral work of the clinic

Previous studies have shown that the birth of a child with developmental problems can give rise to a culture of blame; affecting the views not only of the parents themselves who question their lifestyle and health behaviours, but also among members of the wider family (refs). Referral to the genetics clinic, its association with inherited 'familial' conditions, and the subsequent investigations of their child and their family (such as the examination of the family tree or 'pedigree') in the process of diagnosing a genetic syndrome meant that parents were often concerned that they had been the cause of the disorder. In effect, this meant that parents scrutinised themselves and their wider family for an associated disorder or for signs that they could have contributed to or caused their child's condition in some way. This also extended to their own behaviour and lifestyle to try to make sense of their what had happened. In addition, parents reported that they in turn were scrutinised by other members of their family for signs that they may have caused the condition, what we have described elsewhere as 'mutual surveillance' (Featherstone et al, 2005). This led to complex beliefs about the aetiology of their child's condition and understandings of inheritance and causation. Thus, because a genetic diagnosis has the potential to identify the origins of the condition and (if familial) the potential route of inheritance, the clinic also provides the opportunity for the attribution of blame and responsibility for transmission.

Whilst in many ways responsible for causing these concerns, the clinic provided parents with a discreet and professional space in which to confide their fears about their role in causing their child's condition. Within this setting, parents often confessed to acts or omissions, particularly connected to their lifestyle that they felt may be associated with the cause of their child's problems in some way. Parents often appeared to be highly anxious when they attended the clinic, particularly if this was their first appointment.

During this initial consultation, a detailed history was routinely taken and this was often the point at which parents chose to inform the clinician about behaviour or events that they believe may have contributed to or caused their child's problems. The style of such disclosures often took the form of a confessional, their speech was often hesitant, and they appeared to be relieved once they had unburdened themselves of what had been secret fears. The finding of a genetic cause meant that parents could address these feelings of guilt and responsibility and this is consistent with the findings of earlier studies (Carmichael et al., 1999; Collins et al., 2001; Barr & Millar, 2003). Thus, attending the clinic allowed parents to discuss their often complex feelings of guilt.

Armstrong et al. (1998) suggests that clients (whose clinic transcripts they studied) who offered such non-genetic explanations, such as diet or medication, in response to their diagnosis were doing so as a diversionary tactic, a way in which they could evade the reality of a genetic cause for the condition. However, our data suggest that parental scrutiny of their behaviour and lifestyle in the light of a genetic diagnosis is a way for them and their families to make sense of the condition. These families are not avoiding the genetic nature of their child's condition but are seeking ways to understand why this has happened to their child.

The Clinic as a Site of Reassurance

The clinic functions as an important site of reassurance for both parents and the clinical team. The pursuit of a genetic diagnosis often took a number of years, and in some cases never led to an explicit diagnosis of a named syndrome, although in such cases, the clinic was usually able to provide parents with the likely cause of their child's problems. Although the provision of a diagnosis was important for the majority of parents, their connection with the clinic often did not stop at that point. Parents felt that they had an ongoing relationship with the clinical genetics team, which was based upon factors other than that of risk assessment. They continued to use the clinic as an important point of reference to monitor their child's development and valued the regular progress reviews. They all felt that even if they stopped attending; they were in no doubt that they could contact the clinic if they had concerns about their child at some point in the future. Bernhardt et al. (2000) similarly found that families valued the ongoing contact with the clinic, particularly having their child's development assessed by someone regarded as an expert in the field.

More recently, Barr and Millar (2003) have reported that the genetics service attended by the families they interviewed did not provide ongoing support once a diagnosis had been provided, which suggests that there is some variation in the organisation of clinical services. While previous studies have argued for ongoing contact between the genetics service and parents of children with inherited conditions (refs), this study shows that a genetics service that is able to sustain a relationship over a period of time, with contact

not limited to a diagnostic and future risk assessment role, can play a wider role in supporting parents.

The sentimental repair work of the clinic

The clinical management of children has been a major theme in the sociological analysis of medical institutions and the attribution of identities (cf. Bluebond-Langner 1978). The intervention of medical services and members of other caring professions in the lives of children and their families gives rise to delicate moral and identity-work. The identity and value of the child may be under threat, and may be re-affirmed through interactional face-work; the moral worth of parents may also be a topic of identity-work in both professionalised and everyday encounters (cf. Voysey 1975). As Davis and Strong (1976) point out, the value and attractiveness of children is repeatedly affirmed in the context of paediatric encounters (Davis and Strong 1976). The maxim 'aren't children wonderful' (maintained irrespective of their actual performance) captures the taken-for-granted value of children. Likewise, Voysey's analysis of parental accounts in families with a child with disabilities demonstrates vividly the moral work of accounting for 'normal' parenting and 'normal' family life in the face of others' presumptions of family difficulty (Voysey 1975). Such work has salience for the work of the genetics clinic, particularly within the specialism of dysmorphology.

Dysmorphia in children clearly throws into relief the topic of identity-work in medical settings. First, dysmorphia gives rise to actual or potential threats to the attributed identity of the child, through the potentially discreditable implications of spoiled appearance (Goffman 1963). Secondly, the fact that it is implicated in *genetic* medicine creates the potential for moral threats to the parents' and their families identities. An important aspect of the clinical consultations observed in this study was the work of repairing the perceptions of identity of the child and the family. Many of the families reported a wide range of negative reactions to their child in the wider community (and in some cases by other professionals) that they found upsetting and stigmatising.

In most cases, these children had learning disabilities, and often had dysmorphic features of varying severity, some of which relate to the face or head. Attendance at the clinic meant that parents were in an environment where their child was routinely admired by the clinical team, rather than treated as a potential source of shame and stigma. Irrespective of the apparent severity of their dysmorphic features, all these children were described in similarly sentimental terms. In addition, a wide range of behavioural characteristics displayed by children likely to be interpreted in other formal settings as problematic or disruptive were actively accepted and enjoyed within the clinic.

This finding is interesting- it might be felt that the work of the dysmorphology clinic would contribute to parental feelings of stigma and

shame. As we have documented elsewhere (Featherstone et al, 2005) within these clinics both the children and their families are scrutinised intensely. Children's bodies and faces are closely scrutinised for 'abnormalities' and are routinely photographed. Whilst parents and other family members may also be physically examined and a family history taken which encourage family stories of any abnormalities.

The clinical team used a number of devices to achieve this repair work. They commonly compared the child's behaviour to that experienced by 'normal' families, the clinician's own family or by commenting on the universal nature of problems faced by parents. Despite often-severe developmental delay, or abnormalities being present, the clinical team explicitly grouped these children with other 'normal' children, emphasizing their sameness. Where families feel the stigma of having a child who is not completely "normal", which can be seen in external features or behavioural problems, the clinician redresses the balance: positively highlighting the child's abilities and providing assurance about their development.

This research suggests that ongoing contact with the genetics clinic serves to fill a wider, and much-valued, role than simply that of providing a diagnosis. Although obtaining a diagnosis can be very important to families, such ongoing contact can provide important support for the parents and may well be in direct contrast to the attitudes they encounter in other areas of their life.