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Family ties in genes and stories: the importance of value and recognition in the narratives people tell of family

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Abstract

Diagnosis in paediatric genetics involves a combination of technologies able to display variation in DNA and clinical discussions with families that concentrate on retrieving family histories. This paper explores the significance of the family tales that genetics brings to the fore. Through discussion of an ESRC-funded ethnographic study of families referred to a paediatric genetic service, the paper explores how genetics and family history intersect in 'relations of exchange' (Latimer, 2013). It draws from sociological work on family that emphasizes the importance of narrative to the formation and maintenance of family ties and the importance of broader social contexts to the kinds of stories that can be told and recognized by others. The paper emphasizes the significance of claims to respectability and value to the narratives people provide of family ties; particularly in contexts where such ties, in the past or the present, are thought of as 'troubling'. Making reference to research by Skeggs and Loveday (2012), it is argued that an important narrative that is drawn upon, in order to claim respectability, is that of being a good parent who protects their children from socially 'risky relations' so that a positive future as a 'subject of value' may be possible.

Keywords: family, genetics, kinship, narrative

Introduction

What makes a grouping of individuals into a recognized 'family' can be defined in a variety of ways. One version is to see them as sharing genes and blood; ties of reproduction and the passing down of genetic legacy (Bouquet, 1996; Finkler, 2001, 2005; Nash, 2004). Another contrasting version is to see them as the collection, sharing and passing on of memory, stories and the legacy of history (Edwards, 2000; Gillis, 1996; Strathern, 1992). Investigations into the genetic causes of differences in childhood development bring these versions of family together through the role of family history in the diagnostic process (alongside biochemical analyses of blood from the child and other family members). Contemporary sociological and anthropological work on paediat-

ric genetics does not propose that gene stories win out over memory stories, but instead considers how, within the space of the clinic, 'relations of exchange' (Latimer, 2013: 17) occur between families sharing their stories and artefacts of family and geneticists sharing their medical explanations of difference and abnormality. These exchanges are informed by families' wishes to understand their child's present and future and geneticists' efforts to establish the validity of their knowledge and expertise. The work of Latimer, Featherstone and colleagues (Featherstone *et al.*, 2005, 2006b) have taken us into the daily practices of genetic clinics, enabling us to understand better what is at stake and how what happens there influences broader understandings of normality, self-hood and inheritance. Their work shows us how notions of family are drawn into the work of clinics. This paper adds to such accounts through a slight, but important, difference: instead of examining how family is drawn into genetics within the space of the clinic (which we have examined in other papers (McLaughlin and Clavering, 2011, 2012), the focus is on how genetics, once outside the space of the clinic, is drawn into the work of family.

Drawing from a study of paediatric genetics, the paper does this via a focus on the significance of different forms of narratives to the production of family boundaries and lives and the work narrative does to protect and defend family relations against suggestions there may be a fault within them (Kellas, 2005). Genetics brings to the fore the possibility that there could be something 'tainted' within a family line; what Featherstone *et al.* (2006a) refer to as 'risky relations'. However, genetics is not the only way that a family line can be brought into question and disrepute. Social history and contemporary associations are of equal or more importance in questioning the value of a family's line (Edwards, 2000; Morgan, 1996). Judgements about a family as being 'troubling' speak to a range of norms in society about work, welfare benefits, 'lifestyle', living arrangements and reproduction that families are judged upon, particularly if such problematic patterns are viewed as being 'passed down' the generations (Gillies, 2005; Levitas, 2012; MacDonald *et al.*, 2014). They are infused with classed, gendered, age, race and sexuality norms, which help police the boundaries of acceptable living (Barrett and McIntosh, 1991; Donzelot, 1997; Lawler, 2002). Such judgements also speak to the continued significance of family as an aspect of people's intimate lives that informs their social position and how they can be mis/recognized by others (Bourdieu, 1996; Hamilton, 2012). In the research discussed here, through the analysis, it became clear that some of the participants either saw themselves as part of troubling family ties; or were trying very hard to distance themselves from such associations and that such associations influenced both their route into genetics and their responses to the diagnostic practices that followed. This paper examines the distinctive dynamics of exchange that occurred for these families and considers the significance of their 'troubling' status to such exchanges.

This is done via a focus on narrative. Both genetic accounts of family pedigree and stories of past and present relations are narratives that inform

how people think about the nature of family ties and their boundaries. The paper begins by highlighting sociological work examining the importance of narrative to the formation, maintenance and fracturing of family ties. Then, after briefly describing the study, the paper discusses the narratives different family members produced about their family connections, exploring how genetics did and did not come into such narratives and what role those narratives appeared to play, within the context of genetically and socially troubling ties. Overall the paper argues that the participants made use of narratives about family to distance themselves and others (particularly children) from problematic pasts and relations. They did this in order to provide some protection against such dis-valued associations, associations framed primarily as social rather than genetic.

Narratives of family

Sociology has a long-term interest with the social significance of narratives and memory (Lawler, 2008). Such work acknowledges that the narratives we tell of ourselves and the world around us are more than personal recollections (Lindemann, 2001; Prager, 1998). Instead they are 'the everyday operations of social and cultural relationships which are performed in the creation of memory narratives and embodied in the resulting cultural texts' (Keightley, 2008: 176). What makes a narrative meaningful is the relationships that emerge in the telling of it and how it draws from existing narratives in order to be understood. Of particular importance are the stories we tell of those we call 'family'. Across both anthropology and sociology there is now a substantial body of work examining the social production of family ties and understandings of kinship (Franklin and McKinnon, 2001; Jamieson, 1998; Smart and Neale, 1999; Strathern, 1992). While people's familial connections may be narrated as permanent, contemporary accounts of family highlight the significant work that lies behind the making of such connections. Carsten argues that 'for most people kinship constitutes one of the most important areas for their creative energy' (2004: 9). She makes an important distinction between family as something 'given' to us, and also something that is 'made'. This has strong echoes with historian Gillis's (1996) influential distinction between the families we 'live with' and those we 'live by'; that is, the myths and stories that act as windows into what we value as being family. What this discussion of narrative points towards is how the narratives embedded in the stories people tell about family do not just provide insight into a family's identity (as articulated by that person), they help inform the development of that identity (Kellas, 2005; Mason, 2004; Misztal, 2003; Smart, 2007). As Finch notes 'narratives are seen as stories which people tell to themselves and to others about their own family relationships, which enable them to be understood and situated as part of an accepted repertoire of what "family" means' (2007: 78).

The significance of cultural recognition and governance dynamics around families is seen most clearly when scrutiny falls on those deemed to have values, lives, pasts which fall outside acceptability (Lawler, 2002). Not all family narratives, histories and relations are given equal value. Certain families seeking to establish and have recognized their familial affinities, struggle to respond to pre-existing narratives that assert they are of little or no value because of their association with a range of troubling social categories: the young single mother family, the family 'living on benefits', the lesbians raising children together etc. Some sociologists have suggested that there has been an expansion in forms of family living and, alongside, greater acceptance of multiple types of kinship making (Beck and Beck-Gernsheim, 2001; Giddens, 1991). However, such varied forms of life appear to still strive to have others recognize them as family and of comparative value to established norms of what families contain and do (Jamieson, 1998; Taylor, 2007, 2009). Finch's (2007) work on family narratives emphasizes the use people make of displays of family life and ritual in order that others recognize their relationships as familial and appropriate. Skeggs speaks of the 'regimes of value' (2011) – in her account most closely linked to class – within society that validate the boundaries of acceptability associated with different types of family life. Her interest, drawing from Bourdieu, is in how some subjects come to be recognized as 'subjects of value' while others are not.

One of the main subjects that lack value in the contemporary imaginary are those whose class position, varied practices and embodiments mark them as 'non-propelling, non-future accruing subject[s]' (Skeggs and Loveday, 2012: 475). One example of such subjects are the infamous (and non-existent – Levitas, 2012) 'troubled families' given prominence by the current UK Conservative/Liberal Democrat coalition government, who are narrated as being marked by multi-generational patterns of unemployment, criminality and uncontrolled reproduction. Skeggs highlights how those tarred by such narratives produce their own counter narratives – often by valuing the very relationships said to define their lack of respectability – but what they cannot guarantee is that such counter values will be recognized by others. Therefore, Skeggs and Loveday ask, 'How do we comprehend what value means to those symbolically positioned to have no value, the wrong culture and defective psychology, who are held morally responsible for all the structural inequalities they inherit and by which they are positioned' (2012: 486–487)?

In disputes over family value, how might genetics come into this? Does it provide a counter to narratives of mis-recognition, or does it enable another avenue for questioning the validity of particular family relationships and ways of living? It certainly seems possible that stories of genetic inheritance could 'lock' people in associations of 'bad blood'. Public discourses around genetics often paint simplistic accounts of how genes shape us. Versions of self-hood as normal, abnormal, as the worried well, as the carrier of a syndrome rather than a disease, point to the ways in which genetics is becoming integral 'to body-world relations, and ideas of personhood, identity and belonging' (Latimer,

2013: 7). As the scope of genetic science and application in healthcare continues to expand, it seems feasible that genetic conceptions of both who is a family and what the character of that family is, could become powerful markers supporting other socio-cultural narratives of good and bad families. A narrative that is particularly powerful because of the connection it appears to forge to the past via biological inheritance. Traces of the past remain alive at the molecular level (Edwards, 2005) making it impossible to become a 'future oriented' subject.

The ethnographic work in genetic clinics referred to earlier are important first steps in seeking to understand how stories framed in the medical realm of genetics may inform the validation and invalidation of families through the stories told by and of them (Featherstone *et al.*, 2006a; Latimer, 2007; Shaw, 2003). However, this work also stresses that what will occur is not just informed by what happens in the clinic. As Latimer (2013) argues, the influence of genetic narratives of family relationship and character will occur through how they become embedded in everyday life and social fabric. This is not about how a medical narrative either usurps or confirms an existing family narrative, but how they work together to produce versions of what a family is in terms of both its members and character. Latimer's focus is on 'relations of exchange' that occur in the space of the clinic and the work done there by families in informing the narratives of genetics. However, the clinic is not the only space within which genetics is made meaningful, the relations of exchange are far broader, involving multiple social authoritative others in the production and validation of family narratives, enmeshed in the existing socio-cultural narratives genetics may or may not become embedded within. Latimer's focus was on how families were drawn into the work of genetics, so the focus on clinics and their positionings within the institutional relations of medicine and science was completely legitimate. Examining how genetics may become part of the work of families and their broader narrative exchanges requires a drawing out from the clinic to the broader social worlds of families in order to think about how families (a) manage problematic pasts brought to the foreground by genetics, and (b) draw genetics into the management of those pasts. In doing so the intent is to suggest that family members are active in the ways in which they make use of different narrative possibilities, informed as much, if not more so, by their social position, than by the particular properties of genetic narratives.

Our work in a genetics clinic brought us into contact with families managing social narratives about the right kinds of family and family relations in light of both genetic interest in their children and their varied social position. While we had not sought to recruit families with complex histories to be managed, during the analysis stage it became clear that within our sample there were families managing problematic family stories and pasts and that this influenced both their engagement with genetics and their engagement with us (including using participation in our research as an opportunity to tell a different story about who they were). In addition, what also came through

analysis was that what these families also shared were children whose developmental differences were primarily around disruptive behaviour and or learning disability. Such families primarily came to genetics seeking an explanation for the differences in their children's development that could counter narratives of parental failure or neglect that undermined claims to be a good family (explored in detail in another paper (McLaughlin and Clavering, 2011). For such families, they may come to genetics looking for an alternative narrative for their children and for themselves; however, the risk is that genetics, through its interest in inheritance and family history may instead emphasize the family's troubling qualities (Raspberry and Skinner, 2007). Our paper explores how such families managed this risk.

Methodology

This article is based on data from fieldwork with 26 families whose young child had been referred to a genetic service in the UK.[1] 'Families' here refer to close relations to the child, the boundaries of who that included was established (and at times changed) through the research process. The service in question is based within one Hospital Trust, but undertakes clinics across a large rural and urban region that covers much of the north of England. Referrals, usually triggered by a paediatrician, lead to an initial consultation at one of the clinics. If, after an initial visual examination of the child and questions directed at the parents regarding family history, the geneticist thinks there is something they can look for, then further consultations and tests occur.

The methodological approach was to follow each family over time, going with them into the different settings of their lives and listening to the perspectives of multiple actors, including parents, siblings, other significant family members and the children who had been referred (other publications have explored the multiple perspectives within families – McLaughlin, 2014). The majority of the families we worked with were recruited as the process of first referral to the genetics service was underway and we followed them through their first consultation and beyond. A smaller group were several years on from referral and we spoke with them to examine their experiences of living with or without a diagnosis. In discussions below, where relevant to the analysis, we will indicate which families were new referrals, and which were not. Fieldwork data was generated through a mix of qualitative longitudinal interviews and non-participant observation in clinical and non-clinical encounters. In addition, young people and children had the option of filling in journals with their stories, drawings and thoughts on what family and genetics meant to them. Recruitment occurred through letters of invitation sent via the genetic service and through publicizing the research in regional newsletters for families with disabled children.

A number of measures were put in place, as part of the overall approach towards protecting the anonymity of the participants, to ensure that the clinic

did not know which families went forward to be participants. Given the rare nature of some of the syndromes, information on specific diagnoses is not given here and aspects of the specific variations found have been altered. Information about the families or the clinic that together could potentially identify them is not included. All names used below are fictional and people primarily are identified via their familial relationship to the child who had been referred to the genetic service. The project obtained ethical approval via the Local Research Ethics Committee (LREC) of the NHS National Research Ethics Service (NRES). The data analysis within the project involved independent and then shared coding of transcripts and notes within the project team. This process was influenced by a theoretical coding frame that was then applied to the transcripts, observation notes and textual material.

Recruitment did not seek particular class groupings within the sample; however, as part of placing families within their socio-cultural background and position, participants (as individuals rather than as 'a family') were asked a range of broad demographic questions at the beginning of the first interview, including what class they identified with. A majority of adult participants (29 out of 44) self-defined as working class, while 2 defined themselves as lower class, 4 middle class and 9 refused to give a class label (within that group material markers would suggest working-class associations). The majority of those who defined themselves as working class spoke of being from the 'respectable' working class, as a clear narrative marker of the distance they wished to produce between themselves and others they could be 'mistaken' for. The analysis indicated links between how those who spoke of being working class, lower class or no class managed the introduction of genetics into their lives via their child's referral, their framing of family boundaries, relations and pasts and their wish to be recognized as good families and parents.

The shape and boundaries of family ties

The narratives the participants used to describe who their family was defined the boundaries of who was and was not family. One common motif was that those who had walked out on their family in the past were rarely let back in:

> My nana who died, unfortunately when my oldest was born she contacted my real father to let him know he was a granddad. And apparently he's waiting to hear from us. And I said, well he'll be waiting a damned long time then won't he! 'Cos the last time I saw him I was five, [pause] and I said at the end of the day I haven't had a father for thirty five years so it's a bit late for that one. And I gather he went on and married two more times and there's like a *load* more children, you know. I've got various relatives running around England. (Mother, Adams Family, Int 2/3)

The difficulty was that the clinic often became interested in such members if suspicions of inheritance were raised. In such contexts people were usually

resistant in drawing such family members back in to allow them to be contacted, believing that retaining made boundaries was more important than establishing genetic connections. The Adams family had been referred because the mother disagreed with a diagnosis of severe autism that had been given to one of her sons. During the course of the research the geneticists thought they had identified a possible genetic trait which would explain the son's behavioural issues. The trait they wanted to explore is one that is inherited and is usually passed down the maternal line; because of this the geneticists were interested in exploring whether the maternal grandmother had the same genetic variation as her grandson. However, the grandmother refused to have blood tests. When the mother explained the actions of her child's grandmother she linked it to her past. As a child the grandmother had been put into care because she was born out of wedlock, later her mother married and was able to get her back, and she was subsequently adopted by the husband. This past was rarely discussed by the grandmother and led to a dislike of exploring family history. In response, the mother suggested there was little to be gained by trying to establish genetic inheritance:

> when we first got the letter saying it was from me, I said, I'm sorry, if you've got any more questions that's probably gonna be where it ends, realistically . . . if it's my mum's side it kind of closes there. So I mean I've said to my husband, I said if you want answers, you're probably not gonna get them realistically, because as much as he can trace his family tree back to the eighteen hundreds, I said mine unfortunately kind of ends with me mother, basically. (Mother, Adams Family, A1 Int 3/3)

The mother's articulation that 'it ends here' was said with little regret. It represents, as others also articulated, a disinterest with the past and instead an emphasis on the future. Such responses were associated with histories where the culturally recognized narratives that would frame them would bring the family into question and disrepute. In her first interview the mother had spoken at length of being from the 'respectable' working class, focused on the importance of introducing the values of work and responsibility into her children (which was a key reason for her rejection of the label of autism for her son). The mother in the Collins' family had also been estranged from the maternal grandfather of her referred daughter for many years. The referral had been several years before, but it was only recently that a genetic trait had been identified in both daughter and mother, prompting the geneticists to want contact with the daughter's granddad to further explore the pattern of inheritance. Both the mother and the maternal grandmother refused to contact the child's grandfather; instead the mother emphasized the importance of the future, rather than the past, to the child:

> I think it might come from my dad because I can see similar problems with him, though I've never talked to him. That line of questioning is not avail-

able. The only one who could contact him is my mam and she has said she doesn't want to get him involved. I'm ok about this. The important thing now really is looking ahead (Mother, Collins Family, Int 1/1)

Greater importance was given in the majority of families to maintaining the break with unknown or unwanted blood relatives, than to establishing the significance of genetic inheritance – even when a genetic diagnosis had been sought and welcomed. The mother in the Collins family (and the daughter) valued that they shared the same unusual genetic variation and both spoke of it creating a closer bond between them. However, this did not mean they wanted to establish genetic connections to those they had placed in their past and removed from their lives and life narratives. A genetic connection had to match an existing and valued social connection to be wanted.

The most explicit attempt at creating a boundary between the past and the present was by two parents who had recently adopted two children with behavioural issues who were now being seen by the genetics service. When they adopted the children they were aware that they came from a 'troubled' background. Very early on, against the recommendation of social workers, they changed the name of the youngest child and removed the middle names of the older child. The mother and father explained why the social workers protested and why they went ahead:

> *Mother*: the children's names, because that's the one thing that belongs to them, that's the only thing they've got in life type of thing.
>
> . . .
>
> I mean [daughter] was three and a half when she came to us and we thought fair enough she knows her name
>
> . . .
>
> We got rid of her middle names legally but stuck with [daughter's name], it's not something that we would've chosen but we thought you know it's not a horrible name or really peculiar name that stands out, we thought we can live with that, but we thought [son's original name], no, we can get away with changing that and we did, and then we were encouraged to keep his middle names and we thought, no. (Mother and Father, Martins Family, Int 1/1)

While the parents recognized that the children's names provided a connection to their past and was in a sense something they owned, the past was so tainted they wanted to create a barrier to it (although they did allow the daughter to keep a box of photographs of her original family, implying they wanted to give some recognition to narratives of original kin). The starkness of the name change can be understood as an attempt to distance the children and the parents from a troubled history that the parents defined as 'shocking'. They

talked of the stories they had heard of violence towards children and animals, of physical and sexual abuse, and of a grandmother who 'turned gay'. They also disliked the children's names, particularly the son's name, because they were unusual – the undercurrent was that the names were a symbol of what they saw as the lower-class values of their original family. The picture they painted is of the chaotic lower-class 'broken' families Skeggs highlights as being read by others as without value. In response the Martins worked hard to create distance between the children and their past (to create a narrative break through the change in name); in the process asserting their role as respectable working-class parents to shape their children's future (the production of new narratives) and in the process aid their development and behavioural problems. While the geneticists, through the social workers, were exploring possible genetic inheritance, the Martins focused on the production of a barrier to that past, in order to imagine they could work towards a better future for the children.

The families discussed so far wanted to project a sense of being 'forward facing' as part of being subjects of value, rather than trapped in difficult, painful relationships and histories. For all participants with links to troubling backgrounds (even if acquired through adoption) the past was something to be cautious about, yet engaged with through the significance it generated for current and future claims of respectability; this was particularly important if aspects of their social position – such as class and gender – could undermine prospects of being seen by others as 'subjects of value'. The problematic relations were represented as in the past, even if still alive. Other families had tricky dilemmas to face in the ongoing recognition problems they faced due to 'risky relations' with whom they had current, if fraught, social relationships and with whom genetics may emphasize connections to.

Present risky relations

For those in the study who defined themselves as lower class or who told a story of working towards a respectable working-class identity, present relations who displayed their connection to 'troubling families' was a problem. In particular they were a problem in the work they were undertaking to give their children, even those with developmental problems, a future. In such attempts a narrative was created that as parents they could – and should – protect their child or children's future and doing so involved management of family ties. This parental role was understood as an important element in being 'future-seeking subjects'.

One mother (Dougherty family) discussed how others challenged her ability to parent due to her social position as a young lone mother from a 'lower class' (her words) background associated with struggles over both money and status. She discussed how she actively limited – rather than broke – her children's contact with other children within the extended family (in

particular her half-brother who shared similar problematic, but in her view worse, behavioural traits to her son). The mother's justification for doing so was that she wanted to instil 'decent' values in her children and time spent with the other children could undermine her efforts. Instead, she worked at creating a safe, clean and crucially 'calm' home, where her children would learn how to behave. Through the cleanliness and quiet of her home she sought to project, and embody through her children's behaviour, a form of respectability beyond what her current financial precarity (Savage *et al.*, 2013; Standing, 2011) and family background suggested to others.

The narratives told around problematic ties also share a framing around the importance of instilling good behaviour in children and that one way of doing this is to protect them from faulty relations. Featherstone *et al.* (2006a) speak of the 'risky relations' created by genetic tales of problematic inheritance. For the families associated with troubling backgrounds in this study, while such genetic risks were spoken of, equal importance was given to the apparent need to manage socially risky relations. Such relations were those who undermined the version of respectability they were seeking to project and have recognized.

Such risky relations were prominent in the narratives of the Carr family whose son had behavioural and learning disabilities, which had led to a referral to the genetic service several years ago, but again only recently had a possible genetic explanation emerged. While both parents had difficult histories, it was the maternal side that had been and was the most scrutinized (the mother described her past and family as 'harrowing') by both geneticists and their local community. The mother described her history as one marked by periods of being in care or her siblings being in care, of absent and changing parental figures, of unstable familial structures and roles (in the past siblings had referred to her as mum) and significant material insecurity and deprivation (while the father defined his class as working class, the mother refused a class position aware of what class others would place her within). She also spoke of a wish to remove herself and her immediate family from her biological relatives; however, she felt she could not. The one thing that provided some protection was a friend of her biological mother who she described as her adopted mother and as being, along with her husband and children, her core family. The Carr family's home, in an economically deprived area, was full of photos, both on the wall and in albums. Much of their interview was spent going through them. The mother's wish to escape her 'real' family was marked by their complete absence within these displays of family which they valued as being the most important possession they had:

Mother: But to me, family is important and if I didn't have these two [pointing to photograph of her 'adopted mum' and her adopted mum's husband], I would rather not have my biological family, I would rather have these two and the family that I've got now. And that would be my life. (Mother and Father, Carr Family, Int 1/1)

The narratives available to her about her background offer little to protect her or her 'immediate family' from social judgement as being one of those problem multi-generation families with problem children they cannot take care of. In addition, almost as proof that her background was problematic, the genetic service had told her that the genetic variation they had identified in her son had come from her:

> *Mother*: So I don't know if, back in my past, or my family's past, that we had a member of the family like the way my son [the child referred to the genetic service] is. [Sighs] But having found out that we might have to have the blood test to figure out how far back it does go. It has thrown up quite a few questions for me. . . . with me being put in the Child Services, and having so many different schools, I've had a poor education that's why I am re-doing my Maths and English. So maybe that's part of it as well. [Pause] With my learning difficulties, and *my* behaviour has rubbed off, passed onto them. Because they can get rather aggressive can't they? Especially [son – proband], 'cos he gets frustrated, quite a lot, when he doesn't get his way, or when he feels like he's not understood. (Mother and Father, Carr Family, Int 1/1)

Her past is now present – genetically – in her son, emphasizing for her the permanence of her connection to her biological family. To protect her children throughout the interviews, via the photographs and the evidence they provide of visual similarity (Hirsch, 2002; McLaughlin, 2014), she highlighted how both the children share many similarities with their father and his side of the extended family. This is both through suggesting that the children take after their father far more than her, but that also they carry a strong resemblance to their dead paternal grandmother:

> *Mother*: Yeah, so dad's eyes . . . they used to think that was our daughter when she was little, it wasn't, it's her dad
>
> . . .
>
> and there [points to photograph of daughter] . . . Looks like her grand-mother . . . When she was younger, [points to photograph of the paternal grandmother as a young girl] that's his mam
>
> . . . .
>
> See, they don't look anything like me, the only thing they've got off me is my hair. (Mother and Father, Carr Family, Int 1/1)

One line of familial inheritance – the paternal – over another – the maternal – was emphasized in the hope that recognition of this connection could counter the line genetics prioritized. Genetics had become another route through which the association with problematic relations undermined desires to be recognized as a family of value.

The risky relations amongst participants in difficult social positions were those associated with the troubled families that are emphasized in current imaginaries within UK welfare debates. Gender and class, unsurprisingly in the current contexts, appeared important policing narratives against which parents felt they had to work in order to be recognized as subjects of value. Being a good, responsible parent was an important way to enact being such a subject; managing their connection to others seen as lacking value or respectability was one way of doing so. A way that was more important than maintaining existing family ties. If faulty relations could not be rejected – in part because genetics appeared to support their permanence – then they should be kept at arm's length to limit the associational damage they could do.

Searching for inheritance

The families we have spoken of so far rejected, or were wary of, genetic attempts to investigate patterns of inheritance within their past and extended families. A minority of other families did want to pursue such explanations (whether to confirm or rule out the presence of a genetic trait within the family line); however, their contrasting approach was still influenced by how such knowledge could be incorporated into their current familial narratives of status and recognition. The mother in the Hardcastle family had spent a great deal of time trying to draw up and work through her children's family tree. This had proved difficult due to a large number of extended relatives (her paternal grandparents had over ten children), multiple broken ties, secrets and silences, particularly around relatives who had been institutionalized and finally, during the study, a refusal by her biological parents to undergo blood tests:

> So what I didn't realise was both me mam and me dad could be carriers of whatever's gone into me, and whatever's been passed into my children. So we could have a double dose of whatever this genetic problem is. But that would never be known until they tested me mam and dad, which is what the big fallout was over, because me mam and dad weren't willing to be tested for my children. [Pause] But whatever that gene is, my kids could have a double dose of it. And not just a single dose, we never *ever* suspected me mam's family, we always suspected me dad because we knew they were all in institutions. (Mother, Hardcastle Family, Int 3/3)

Due to their refusal the mother no longer had contact with her parents (a history of parental abuse also lay behind the fracture, but the refusal to have the tests was framed as the 'final straw') and she said she no longer considered them to be her family:

> And I will never ever speak to them again in their life. I don't have family, my family's [pause] me, and my children. (Mother, Hardcastle Family, Int 3/3)

The narrative the Hardcastle mother provides suggests people have a responsibility to know their past and now that genetics makes things knowable it should be an obligation to participate in what it can discover (a form of Rose's 2006 biological citizenship). In making such an assertion her narrative connects the present to the past in a way other families refused to do. While the narrative bond to the past is different to that made by the others, the rationale can still be connected to issues of value and respectability. The mother was raising her children on her own in local authority housing; the children, the majority of whom displayed a range of developmental and behavioural issues, did not all share the same biological father. The mother described herself as 'Lower class . . . I'm classed as a single parent, benefit scrounger with disabled children' (Mother, Hardcastle Family, Int 1/3). In some ways she recognized she was the kind of family other families in the study who framed themselves as working class or even lower class, did not want to be associated with. Her classed and gendered position risks others reading her as unrespectable and without value. In this context her quest to reopen the past – rather than project the future – can be interpreted as still an attempt to gain respect and respectability. A genetic diagnosis, she hoped, could be used to challenge others who suggested she was a 'benefit scrounger' labelling her children disabled in order to receive welfare support. In addition, she aimed to display responsibility towards her children by doing all she could to unravel the family mysteries that could contribute to identifying what genetic factors lay behind the range of problems they had (throughout the time of the project the genetic service had been unable to identify a specific genetic variation in any of the children). Like the other families she also was keen to display a narrative break ('I don't have family') with those she felt undermined the version of respectability she was battling to have recognized.

Conclusion

In Skeggs and Loveday's (2012) research on contemporary struggles for value they highlight the difficulties those positioned 'as the abject' have in mounting challenges to their marginalization from the 'dominant symbolic'. The parents discussed in this paper all faced such battles, both on their own behalf, but also on behalf of their children. Their strategies included distancing themselves from, or cutting themselves off from, relatives who appeared to undermine claims to respectability. Such decisions were framed by narratives of responsible parenting and keeping a good (calm and clean) home. In contexts with little access to material capital, the symbolism they incorporated into their stories of how they looked after their homes and children, were attempts to be associated with regimes of value. Skeggs and Loveday argue that the contemporary social subject of value is one who enacts ' "compulsory individuality" by which the self displays self-discipline and future-oriented investment in the self-project or self-work ethic' (2012: 475). This remains an important social

subject, one publicly performed via symbolic and material capital not accessible to all. Work and self-reliance (without a celebration of material wealth) were important values for these participants, but this was framed in a context of specific familial relations, rather than an individual self. The importance they gave to doing and symbolizing the right kinds of family values, speaks to the significance of family associations and practices to contemporary regimes of value. One which led them to police (where they felt they could) who entered and who left their family ties.

The families' management of narratives of value and disvalue also influenced their engagement with genetics. While they sought value from genetics as a source of medical explanation of their troubling children, they were uncomfortable with genetic interest in present, distant or hidden relatives who undermined current practices associated with maintaining separation or silence over such 'risky relations'. The importance of examining genetics within its broader landscapes and relations of exchange is seen in how it enables us to appreciate that genetics may bring the past to the fore, but the ways of managing that past are already well established through silences, forgetfulness, and reclaimed accounts that mean it can do little more harm than the 'sins' of the past already do. One way perhaps it can do harm is by suggesting certain ties are permanent because they are embedded in DNA. However, in people's refusals to participate in backward-looking DNA investigations, we see a rejection that the past has anything to do with the present and the future. Some pasts remain toxic to claiming contemporary respectability and recognition. Such risky relations are overwhelmingly associated with ways of living that remain questioned in narratives that link them with problematic practices associated with gender, class and other social categories. Such rhetorics play in to well-established accounts of blame and individualization that create distance between certain kinds of family and respectable society, while shielding that same society from any responsibility over the social structures that generate the vulnerabilities and marginalities such families experience.

A possible puzzle remains over the accounts the participants shared, and that is, why did they share them? It would be counter to the analysis given to suggest they were simply true accounts of what their current and past families authentically were. So why did they share what they did and what possible purpose may have lay behind that 'choice'? The research process did not require, or particularly encourage, the sharing of past family history, but nevertheless participants shared a great deal, often after the simple prompt of 'tell me something about your family'. It was clear that genetic investigations had brought history to the fore, so perhaps it was inevitable that this investigative interest would extend to this project. The research process was also one that created a space within which people felt they could share such stories (and a great deal of time was spent reflecting with them on what it would be appropriate to share more broadly than in that immediate research encounter). While all of this is true, there also is more going on. The research space also

became a space within which they could undertake the work they were doing elsewhere: claiming legitimacy and value to their self-defined family ties and approaches to raising and protecting their scrutinized children. As with the participants in Skeggs and Loveday's research 'they wanted to live life differently, not subject to constant misrecognition and potential devaluation' (2012: 487).

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