Abstract

There are many debates in the social sciences about the certain and uncertain nature of subjectivity and knowledge. Often these debates create competing theoretical camps each hell bent on refuting the other (materialist-idealists; modernist-postmodernists; structuralists-poststructuralists; medical-social). These critiques often fail to engage with the social and material lives of human actors: particularly when those actors occupy positions of relative marginalisation. This paper pitches these debates in emerging accounts of parents of disabled babies, which have emerged from a three year ESRC research study. We highlight the ways in which parents adaptively and strategically use...
and refuse forms of certainty and uncertainty in order to configure ways of living with their children. We suggest that parents are nomadic but also settlers in the journeys with their children and that post/modernist analyses both allow us to make sense of parents’ situated agency within particular social, cultural and material locations.

**Key words:** Disability/Families/Social Theory
Introduction
Contemporary debates within social theory about the possibility of claims to certainty about knowledge, identity and subjectivity have destabilised grand narratives and emphasised recognition of uncertainty (Bauman 1993; Lyotard 1984; Rorty 1989). Postmodern and post-structuralist writers have been at the forefront of such celebrations of contingency, fluidity and deconstruction. In response some critical feminists, disability studies scholars and others have raised political objections to such arguments, advocating in contrast the political necessity of certain truth claims and collective identities. Worryingly, the debate has become stuck in an ‘either or’ scenario where one either advocates transient fluidity or permanent structures of oppression (but rarely both) (Ahmed 1996). This leads us to ask: is this how people live their lives? How do we develop patterns of living, form values, ethics and identities and engage with personal and political questions?

We come to this paper with a nagging concern that those who stress the need to remain certain about identity and truth often speak on behalf of ‘marginalised groups’ who are assumed to require a level of certainty, which others in more privileged positions can live and thrive without. Such critics are presuming to know what marginalised groups need and want, rather than engaging with their experiences of and negotiations with dynamics around certainty, knowledge and identity. They are making assumptions about what constitutes a marginalised group, for example, ‘the black lesbian’ or ‘the disabled family’. The danger is that such arguments and assumptions create simplistic conceptions of who the marginalised individual or community is, participating in the creation of subject positions that bear little similarity to the formation and adoption of individual and collective identity in social practices (Goodley in press-a; Goodley in press-b). Equally problematic are those positions that celebrate fluidity and transience but rarely engage with the messy every day material, social and political relations that go beyond the representational (Jackson 1999; Jackson 2001; Seidman 1997). In work by writers such as Butler (1993) or Fuss (1989), the material is introduced as a subsidiary or by-product of the discursive, always read through the interpretative power of language (McLaughlin 2006b). Newer work in feminist writings and in disability studies is developing ways to cross the divide between the material and the discursive and instead explore how people live with the material and the discursive in co-existence. Our paper seeks to contribute to this developing work by engaging with the lives of parents of disabled children.

This paper explores the ways in which parents of disabled children carve out changing ways of living, which engage with shifting moments of certainty and uncertainty. These arguments emerge out of research we have completed with parents, the background to and methodology involved are summarised below.

Methodology
The ESRC funded research discussed here has explored with parents what is meaningful to them as they live with, care for and love a disabled child or children. We wanted to explore how parents’ understandings of themselves and the world around them changed over time, what transitions occurred within their lives and how they articulated those
changes and responded to them (Brewer 2000; Katz and Csordas 2003). The research, which has taken three and a half years, is based in two English regions (the north east and the midlands); at the centre of the fieldwork are 39 families. The families are divided into two groups, the first group (23 families) have children up to eight years old who have had some form of diagnosis in the last two to three years, the second group (16 families) have children who are younger infants up to three years old who have received some form of diagnosis within the past year of initial contact. With the first group three retrospective in-depth narrative interviews (tape recorded with consent) have been carried out to reflect back on their experiences from the birth of their child. With the second group of parents, over an eighteen month period, a series of three longitudinal narrative interviews have been undertaken (Heyl 2001). With the second group of parents observations of a number of formal and informal care encounters were also undertaken. Alongside the work with the parents mixed focus groups with professionals have also taken place (Clavering and Mclaughlin 2007).

Analysis was developed through a number of strategies. Interview and focus group transcripts and observation notes were entered into Nvivo, alongside team discussion of fieldwork material and conceptual ideas developing from them. Observational notes were examined alongside interviews to explore lived experiences that exemplified the dynamics parents discussed in interviews. At times this approach to analysis was formalised through the workings of ‘node meetings’. This involved subjecting narratives and ethnographic data to points of analysis or themes that were drawn together by the research team as the data were collected (Snow et al. 2003). The range of analysis and discussion allowed ongoing consideration of whether we were developing the most appropriate forms of interview; it allowed us to capture the complexity of the cultures we were investigating; it highlighted new ethnographic spaces to explore; it aided making the data collectively meaningful to us; and it enabled us to reflect on our research questions and through it we began to make the connections between what we were finding and the broader theoretical and policy literature.

When recruiting the parents the deliberate step was taken not to recruit one form of childhood impairment or condition, as this seemed to fit within a medical approach. Instead the basis for a family’s inclusion was that they defined their child as having specific care and support needs and that the child was within the age range used in the project. Via this approach a range of conditions or impairments were obtained. The parents come from a range of different locations and backgrounds that do not sit easily within fixed social classifications. Most were co-habiting heterosexual couples; a small number were single mothers and one parent self-identified as a disabled person. There was a range of ethnicities within and between the different families. In three cases we worked with immigrants to the UK whose first language was not English; interpreters of the family’s choosing were used during the interviews and translations of interview materials provided.

This research was never about considering these families against templates of social theory. However, during our travels with them it seemed to us that they had something of significance to say, which challenges the theoretical certainties of how the current debate
is presented and sheds light on how, in everyday practice, individuals work with and against claims to certainty in both knowledge and subjectivity. Before indicating what parents bring to the debate we will outline its key tensions.

**Seeking uncertainty**

Certainty has become a concept seen as both unavailable and tainted in much of contemporary social theory. Deleuze and Guattari (1987 / 2004) detailed what they saw as the destruction created by the illusion of certainty within understandings of the body, language, and subjectivity in modernity (Markula 2006). Contemporary writers argue that in current times there is greater awareness of the oppressive nature of what Deleuze and Guattari identified within the social condition, in response we are said to be throwing in the towel on believing that we ever can make fundamental claims to both knowing ourselves and knowing the world itself in a true, unaltered form (Flax 1992; Scott 1992). Lyotard (1984) argued that we seek contingent and local narratives, embedded in values of particularity and fluidity. Traditional sources of truth and knowledge, such as medicine and science, are disbelieved and challenged for their hierarchical and exclusionary forms of knowing and studying the world (Foucault, 1990 #795). For Rorty our sense of the world and ourselves is no ‘more than the habitual use of a certain repertoire of terms’ (1989: 22).

Bauman defines the postmodern condition as being marked by people’s strategies ‘to avoid fixation and keep the options open’ (1996: 19). In the modern era, the social conditions within which people formed identities allowed for the illusion of stability and certainty to form, this is no longer possible: ‘no consistent and cohesive life strategy emerges from the experience which can be gathered in such a world’ (1996: 25). He contrasts the pilgrims of modernity, those questing for a real identity, with postmodern consumers who play with short-term symbols of some vaguely articulated and easily forgotten identity. People therefore live in a ‘continuous present’ (1996: 24, original emphasis; see also (Fisher and Goodley in press)). Braidotti summarises the 21st century identity dilemma as being: ‘The point is not to know who we are, but rather what, at last, we want to become’ (2002: 2). To represent these mutations she uses the metaphor of the nomad to explore a form of subjectivity that signifies ‘a complex, heterogeneous, non-unitary entity’ (2002: 72). A subject position so complex that one never obtains it, instead ‘you can never be a nomad, you only go on trying to become nomadic’ (2002: 86, original emphasis). The nomadic figure is at ease with the fluidity of place and identity ‘in a lifestyle based on the permanence of temporary arrangements and the comfort of contingent foundations’ (Braidotti 2002: 11).

Homelessness has become one of the metaphors of uncertainty in contemporary writing. Assuming certainty in identity and knowledge creates a homely sense of comfort and security (De Lauretis 1990). However, in the contemporary age, people increasingly find such comfort either confining or unavailable and seek patterns of identity and knowing within homeless conditions. Being released from homely ties ensures against the freezing of ill fitting formations of self and place (Anzaldúa 1999). Anzaldúa argues that staying within one home does not reflect the multiplicity of boundaries most of us travel through, particularly those whose identities do not fit dominant norms. Home must then become
something one invents, which emerges from the entanglement of border relations to present something distinct.

In much of the contemporary writing discounting certainty in favour of homelessness, one is left with the impression of increased freedom, release and celebration (Bauman 1997). This new world of change opens up the possibility of greater recognition of transient differences and alternative modes of living; this is in contrast to modernity’s banishment of the stranger - such as the disabled stranger - who seemed out of place and disruptive to the illusion of certainty and order (Hughes 2002). Not all contemporary theorists find such claims convincing, indeed for some they are instead dangerously misleading and false.

**Seeking certainty**

Disability writers and feminists are prominent amongst critics expressing unease with the turn towards the celebration of uncertainty over the last two decades. They argue that rejecting the importance of stability and certainty regarding subject status is only appealing to those in a position to voluntarily give it up (Hartsock 1983). Chancer argues that the loss of a notion of the sovereign self would only leave women ‘quite familiarly powerless, filled with self-doubt, unable to assert the ethical necessity and certainty of anything’ (1998: 26); a point also made by Markula (2006). Soper (1993) argues that postmodernism could have only come from a position of privilege and power, a position as yet unavailable to many outside (and inside) the Western world. Uncertainty, transience and homelessness are appealing forms of life for a privileged minority, removed from material hardships, such as real homelessness (Ahmed 1999; Stanley and Wise 2000). Post-structuralist talk of the joy of fluid and playful identities does not include awareness of the material and social inequalities, which enable some more than others to have the space in which to experiment (Fraser 1995; Fraser 1997; Jackson 1995). As Thomas (2006) observes: how is all this talk of culture and identity helping to eradicate the material conditions of disablement? In response social model of disability writers such as Barnes (Barnes, 2006 #2762) and Oliver (2004) call for an unwavering engagement with the ‘real’ and ‘material’ conditions of disablement without the irrelevant distractions of postmodernism.

We would suggest that not all writers exploring uncertainty do so without an eye directed towards those positioned differently in society. Braidotti, for example, has argued ‘one cannot deconstruct a subjectivity one has never been fully granted... In order to announce the death of the subject one must first have gained the right to speak as one’ (1994: 141). Similarly, Deleuze and Guattari (1987/2004) have acknowledged that a complete emptying of the body of subjectivity would be quite literally madness: we need enough of our subject to live. Bauman (1997: 14) argues that not everyone is welcome in the postmodern sphere of fluidity and consumerism; new strangers are created, ‘flawed consumers’ who are ‘objects out of place’ (see also Hughes, 2002). We may all be experiencing uncertainty and transience but ‘here the commonality of our plight ends and the differences begin’ (1997: 93). The difficulty is that while post-structuralist writings may be willing to acknowledge varied experiences within people’s lifeworlds, the work...
itself for the most part remains unwilling to do the kind of social research that could explore this.

The prioritisation of representational analysis, and within this the concentration on research that studies modes of representation rather than modes of living, leads to an unwillingness to connect representations to their social context. In Braidotti’s book *Metamorphoses* (2002) the analysis is of Princess Diana, Michael Jackson and Ballard’s novel *Crash*. The danger in focusing on such cultural artefacts and individual lives, as the basis for arguments about the nature of social relations, is that an analysis of particular consumptions of cultural representation are extrapolated to signify a broader social condition far removed from how people live their intimate and social lives. In Bauman’s work, while one is drawn in by the picture he paints of the shifting postmodern landscape, at the same time, the lack of empirical research in that landscape leaves the argument unfulfilled and unsubstantiated. Social theory and philosophical exploration of changes in social life and the dynamics of identity do not have to be founded in empirical research in order to be legitimate contributions. Their validity comes from the expansive contribution they make to thinking differently and moving social theory and philosophy out of its own certainties and forms of knowing. Nevertheless a division has been constructed between forms of thinking that draw primarily from studies of cultural and consumerist activities and those that draw from empirical studies of material life.

The current division can be crossed by not assuming one has to live a particular privileged life in order for notions of uncertainty and fluidity in identity to be part of life, to matter and to be experienced as positive. Unless we explore how people in difficult social and material situations approach and manage their own identities, we cannot presume they seek certainty in the world around them. From within feminisms, writers such as Skeggs (1997; 2001) and Lawler (2000) have indicated the benefits of doing so, highlighting the forms of agency and fluidity, as well as constraints and denials, present within the representational and consumerist activities of working class women. Similarly, critical pedagogy writers such as Giroux (1992) and McLaren (1989) have broadened materialist critiques of the marketisation of education by using poststructuralist ideas to explain the construction of those learners, teachers and pedagogies that are valued in the current climate at the expense of others. Similarly, in disability studies, contemporary writers have combined analyses of the real and representational through critiques of impairment and disablement {Hughes, 1997 #2672}{Thomas, 1999 #3}, conversations across disability studies and medical sociology (Thomas, 2006) and explorations of the psychological, material and discursive {Marks, 1999 #1663}{Goodley, 2005 #2763}. What such work enables is the acknowledgment of the social and material conditions that marginalise people, while not presenting them as only victims. We need to provide space to highlight the day to day contingent and situated agency that people enact (however socially and materially positioned) and the positive visions that they have of their lives. The research we have done with parents of disabled children has introduced us to such situated agency.

**Seeking certainty and living in uncertainty**
Parents in our study seek certainty about various aspects of their and their children’s lives. However, this is not the only way in which they negotiate the relationships, understandings and issues they experience. What we see over time are adaptive and strategic claims of certainty around particular problematics, while at the same time embracing new forms of uncertainty in their lives and their visions of what the future may hold. Here we look at three key experiences – diagnosis, medical treatment and perspectives on the future – that many of the parents spoke about.

**Diagnosis**

A common narrative from parents, particular mothers, is the battle to obtain a clear diagnosis when their child is born or as s/he begins to develop and appears ‘different’ from other babies and infants. Jane fought hard for a firm diagnosis of autism, which others, both family and professionals were resistant to provide:

John [father] just didn’t want to see what I could see, so it was a constant battle where I kept being the only one, actually sounding obsessed about it … so the last time I went to the paediatrician I actually at one point said, ‘I’m just not happy with his development, there’s just something not right, I don’t know what it is, but has he got like a ‘something syndrome’ or, is he autistic?’ He said, ‘What makes you say he’s autistic?’ … and he just turned around and goes, ‘Well, you can’t just go and self-diagnose your son’. About a year later I actually saw a copy of a letter that he wrote to a midwife saying that I seemed to be obsessed with finding things…. (Jane, First Interview)

There is little doubt that Jane wanted certainty about what was wrong with her son and sought it in the privileged grand narrative of medicine. However, understanding why she sought certainty cannot be removed from the gendered and professional frameworks, which disallowed her from having expertise about her son. The socially recognised certainty of medicine, once provided, validated the particular expertise she had but which was unrecognised due to the gendered assumptions made by others (see Read 2000).

Although Jane had pushed for a diagnosis, she also felt that the time she had with Jack as an infant prior to it was a time unregulated by expectations generated by the criteria associated with the medical diagnosis of the condition:

And probably because he wasn’t diagnosed ‘til later, because I don’t think we would’ve really pushed him to become like, to come out of nappies… So because we tried to treat him as normal as possible and we expected certain things, and I still do, I still don’t let him go around trash ing the house and, you know, putting toilet paper down the toilet, or, whatever he’s up to doing… (Jane, First Interview)

What is telling about this account is the way in which Jane’s appreciation of a time of uncertainty ungoverned by expectations laid down by medical diagnosis sat alongside a desire for Jack to conform to particular socially accepted ways of behaving. Jane wanted to moderate Jack’s behaviour, to ensure he behaves ‘normally’ according to accepted
social norms regarding appropriate child behaviour (a theme that carried on through the three interviews), which she does not challenge as confining. Her approach does not represent an unquestioning adoption of fluidity in subjectivity. As her son grows up she does not want him to always be out of place, thought of as different; instead she wants him to belong, to find a home in broader society. However, her efforts to shape his behaviour and identity are not guided by a diagnosis or by professional medically validated forms of therapy for children such as Jack. Her choices about how much to shape Jack’s behaviour against the norms of society are guided by social recognition of the costs of difference (see also Traustadottir 1995). In this way she is a participant shaping the social conditions within which she lives with her son.

Debbie and her husband Bob have a 3 year old boy (Frank) who was born premature and now has a tracheotomy tube. In the first year of his life it was expected that it would be a temporary problem, however, when the fieldwork began consultants changed their opinion and were now suggesting it was likely to be permanent. In response the parents shifted their expectation from a wish to know for definite what lay ahead for Frank and the dream that medicine could cure him (see Landsman 2003; Larson 1998), towards a more everyday nomadic approach, evocative of Bauman’s continuous present, which focused on Frank growing up with or without the ‘trachy’:

Bob and I have obviously spoken about it, and we now see Frank as, he’s got this trachy’, and he might always have this trachy’, so we’re far better off, he’s a normal little boy who happens to have a trachy’. Because, to cope with that every time he goes into hospital, to think that it might be reversed, it’s not worth it because you are just preparing yourself for being let down. And what we found was we weren’t letting Frank be Frank, and as a family we weren’t just living a normal life. (Debbie, First Interview)

Genetic diagnoses are complex and rarely immediate. Surrounding family members can push for a label, something to understand, comprehend and ‘come to terms with’; doctors can become entranced by the quest for a category that defines the child, proves their suspicions / professional hunches to be true, and solves the puzzle. Parents are mediating between these quests, both seeking to make sense of possible narratives offering certainty for understanding their young child, while also appreciating the costs of seeking meaning through genetics:

But (laughs) it’s just the way people are, I think they prefer it when there’s a label there because then they can deal with it a lot easier. I mean especially the family. The latest one, a rare genetic condition was mentioned. So they’re all now, ‘oh, oh I was talking to my friend the other day and I mentioned that Lauren has that condition.’ And I’m like, ‘no, we don’t know that she has it (laughs) will you stop’. We like people to be pigeonholed in a certain area and until it’s actually happened they don’t know how to deal with anything. (Gill, First Interview)
The extended nature of genetic exploration means that some parents select those aspects of the process that they are willing to participate in. David and Karen’s baby Daniel is suspected of having a particular condition that leads to infantile spasms and development problems. After several months of treatments to deal with the spasms, alongside appointments to establish whether it was this condition, the parents decided to leave the naming process to the geneticists while concentrating their energies on treatments that limited his spasms, improved his development and allowed him to spend time with other children:

I mean we weren’t sleeping, we weren’t eating properly, you know, it was kind of everything just up in the air. And then it was one day we just said, you know, we’ve got to stop this, we’ve got other kids …. They were noticing a difference in our moods and the way, things were for us. And, it just had to be one day, we just said, you know, right from this day forward, as long as Daniel’s happy, and he’s doing fine, then nothing else matters. (David, Second Interview)

What they realised over time was that the supposed certainty naming the condition gave was illusionary. Instead, it offers them and their child very little of value as it is a shorthand summary few outside the genetic community understand. In contrast, seeking that name has the potential for huge costs, disturbing their relationship with their baby, shaping the nature of that developing relationship and acting as a narrative that cloaks out everything else of value within their connection to Daniel (see also Goodley and Tregaskis 2006). Searching for stability and a home within a named condition would never provide security and comfort.

Obtaining a diagnosis is a particularly fraught experience if suspicions of medical negligence or error are involved. In such cases parents may make a strong push to establish exactly what has happened in order to try to uncover who is accountable. This was particularly the case for two families, who happened to be new immigrants to this country:

After Ali’s birth I noticed something different about her head. The place where the skull needs to join up had a much larger soft area, much larger than usual. I mentioned this to the health visitor who reassured me and said it was okay. But I suspected something was not right for a long time. …When I went to the doctors to ask them about this, they suggested it was a family trait. I didn’t think this was very helpful, none of my other children have large heads nor does anyone else in my or my husband’s family…. (Sameera, Second Interview, Translator involved)

The diagnosis - water on the brain - finally occurred, while on a family visit to Bangladesh. Through the alternative opinion, which was accepted six months after their return to the UK, the false certainty of Western medicine was successfully challenged by a non-Western approach not blinded by notions that certain babies have larger heads.
Faced with similar rejection and denial over a suspected medical error during labour, which the parents believe contributed to the physical and learning disabilities their baby faces, the other immigrant family sought redress through the law:

…. they will be in prison, yes, not to leave the prison any more, stay there. It’s not to kill them, because to kill them is not enough. Because when people kill somebody then the suffering is stopped, and that’s not what I want. What I want is to know those doctors in the hospital… for those people only to lose their jobs and to work in a very degrading kind of work… it’s just that they get the punishment for the things they have done to my child… (Corinne, First Interview, Translator involved)

Corinne and her husband Luis’s decision to seek legal redress could be read as validating the impartiality and certainty of law as an arbiter of questions of justice. However, we would argue their choice is, instead, a culturally embedded one. Corinne and her family are new immigrants to the UK; looking around them they view legal punishment as the culturally dominant form of response to issues of harm:

I understand that it is a different culture, and in the culture if you steal something you go to prison, you pay for something wrong you have done… That’s the way I am thinking about it, I see how things are here in this country (Corinne, First Interview, Translator involved).

Corinne seeks the legal avenue not out of a belief in the universality and certainty of law; instead the choice is an interpretation of the cultural position of law within a western country. Her approach also reflects the dominance of monitory penalty within the West; what causes people pain is to rob them of their financial security, career position and status. Positioned as socially marginalised, Corinne adopts the language of law to be both recognised by others, and to dispel the notion that her social position makes it impossible for her to challenge those who see themselves as having a higher and more powerful status than her.

Few parents with a baby or an infant developing differently refuse to go through a diagnostic journey. Rarely do parents find a new home; instead they continue to adopt transient meanings for their child’s condition and possible futures. They seek to ensure that their child does not become contained, categorised, subjectified within a diagnosis; a false home disallowing other possibilities for the child’s progress. The ways in which the parents discussed here are responding to their journey sits within the mode of living and knowing Deleuze and Guattari (1987/2004) term appropriation. As one of us has articulated elsewhere (Goodley, in press-a), appropriation enables the nomadic parent to self-fashion their children’s becomings through using various discourses of the subject that are available and deemed useful, depending upon the time and place (see also Weiss 1999). Parents of disabled babies are capable of using normative and normalising practices of healthcare. Yet, they are also willing to walk away from the illusory promise of certainty: immersing themselves in more uncertain, open and loving places.
**Medical treatment**
Parents have to spend significant amounts of time providing medical treatment for their children. As such it becomes an important site where parents both follow the path laid down by medicine and, at times, reject it. Lisa, whose 3 year old daughter Zoe has cerebral palsy, spoke of striving to follow the treatments and exercises prescribed by the physiotherapists in order for her to improve. She put a huge amount of pressure on herself in order to prove to others that her child was developing. At the same time she questioned her ability to aid her child:

She has her physiotherapy, which I do, I do with her. I don’t do half as much as I’m supposed to because she just won’t tolerate it at all… It’s like I’ve been taking her up to Pelican school because I really want her in there and in order to do that I’ve got to prove to the education authority that she will benefit from their methods… I know if she went to school there, and I wasn’t there she’d just do fine. But because I’m there she just wants to be sitting on my knee and just wants cuddles and wants us to give her a drink and, and she just screams… I quite often feel I’m not the right person to look after her, [pause] because I feel like she’s not coming up to her potential with me because she’s still so much a baby. (Lisa, First Interview)

Lisa follows the prescriptive requirements of physiotherapy for the promise of Zoe being allowed into the school that is her first choice; she is following this ritual not out of a belief in the superiority of medical knowledge to make her daughter better, but out of a regulative requirement to perform the role of the good and compliant mother (a role she feels others doubt she can achieve because she is young and single).

Kay, who is a qualified paediatrician, like Lisa is keen to participate in treatments that help her three year old son Joe who has been diagnosed with learning and physical disabilities. However, she does not want to go along with treatments that are too rigid in their approach and understanding of development. Medical treatments have to make sense and be achievable in a messy world; they need to respond to the child as a whole, rather than simply viewing them as a developmental problem/failure:

And the portage worker is an example of somebody who came and just added hugely to that, and did nothing constructive to help. And one time brought me like a chart to fill in and tick off tasks each day, to, each day, ‘achieved’, ‘not achieved’, ‘partially achieved’, [pause] which is just too controlling and you can’t do that… I felt she was policing how much I was doing each day, because she seemed to be disappointed with the level of progress that Joe was making. (Kay, Second Interview)

Kay, with the authority of medicine and her status as a married, middle class mother - unlike Lisa, who already is judged by others to be irresponsible and negligent - has a space to resist and reject the treatments prescribed for Joe. The regulatory treatment regime Lisa feels she must try to follow to validate her mothering, Kay rejects, not because she is a more confident mother, but because she has a set of cultural and material
resources at her disposal that make it socially feasible for her to do so. Their difference in approach does not signal any weaker or stronger faith in the certainty of medicine. If it was we would expect Kay to be the more willing treatment advocate. Instead the differences between them point to the subjective calculation they make about what they can do for their child in the particular social position they live within. As Shakespeare (2006) notes understandings of disability and impairment benefit from acknowledgement of the impact of social class.

Debbie, the mother of Frank, in the second interview reflected on how her life with him was changing; in particular she talked of the greater distance she was seeking to create between their life and the medical world:

We have a normal little boy who’s a lovely normal little boy but he just happens to have a trachy. And I think our approach has changed because this is our life and we want Frank to have a normal life. Other than him having the trachy he’s just an average little boy…. So then your approach does change because you don’t, we’ve got other things to do, we don’t want to be sitting in hospitals if things aren’t important.

Debbie cut down the number of interactions Frank had with medical professionals in order to reclaim family life and allow him the space to be a child as he grew up, rather than a medical problem. Over time parents were more willing to question the necessity of treatments laid down for them, by reducing the presence of discourses and values of medicine in their lives, they created an expansive and creative space to just be with their children.

Parents recognise the necessity and benefits of medical treatments for their children. Their approach to them, though, is not unquestioning or without scepticism about their promise. They often challenge forms of intervention that do not appreciate their intimate knowledge of their children nor fit with the messy nomadic world of family life. While social position influences the form and degree of challenge they make, it does not determine it. Instead parents at times make claims to certainty or reject the requirements of certainty, in order to move beyond the social position they are assumed to be located within.

What the future holds
From the time a baby is born all parents imagine what the future will hold for them. These ideas will be influenced by dominant narratives associated with the trajectory of the ‘proper family’. The introduction of disability into a family shatters the presumed certainty of such possible futures. This has obvious links with the concept of biographical disruption (Bury 1982), which is a popular notion in medical sociology. Parents, in differing ways, reorient their future expectations, living without the guarantee of a presumed known future (see Fisher and Goodley in press; McLaughlin2006a). This reorientation is, however, not the same as that presented by Bury. Parents do not necessarily seek, as Bury argues, to resolve biographical disruption, to create a new sense
of certainty and map for the future. Instead, for some, disruption, ambiguity, and uncertainty are incorporated into their stories for the future for them and their children.

In response to the diagnosis of autism, which Jane had fought for, looking to the long term future she felt that what she had imagined was no longer available. This, understandably, caused great anxiety:

‘Well, you know, am I going to be a carer for the rest of my life?’ They said, ‘oh well, you know, he’s only four years old, and what on earth do you want to think things like that for?’ and I said, ‘Well, this may sound really stupid,’ I says, ‘but I’ve been saving up for him to go to university, and this is the way I wanted his life mapped out, I wanted him to have everything that I didn’t have…’ (Jane, First Interview)

For other parents, particularly for those where time had passed from the initial diagnosis, living with the uncertainty of not knowing the future became less significant and in some ways opened up opportunities and choices previously thought impossible or irrational. Kay, in her second interview, described how her family was being released from future scenarios to find new patterns of family and individual life that they were growing from and which removed them from ‘normal’ narratives of the good family:

And, we haven’t gone stupid with kind of risk-taking [laughs] behaviour and things like that but it has given us, I think a lot more freedom. Steven’s packed in his job now and he’s doing supply teaching and he never ever dreamed of doing that. He would have applied for deputy headships, we were both on this driven career path which we both stepped off and let go of. And once you do that it gives you a lot more freedom, and you think, well, you know, I don’t have to do this thing that I’ve been planning for the past ten years or whatever, building up to. There’s loads of other opportunities out there, and just taking time to stop and think it, but that’s been really good. (Kay, Second Interview)

Indeed, Kay and her partner found themselves contemplating a rejection of the certainty of measurement criteria associated with successful child development and growth:

Also I think it’s been good with the other children too because I think a lot of parents or friends get into this trap with their children where they’re very, I mean they do want the best for them, but are very into kind of pushing them into school work, clubs, and this and that and the other. I look at Chloe [their non-disabled child] and think she can walk, she can talk, she’s healthy, she’s happy. You know, I encourage her with things but not, I don’t get so worked up that she hasn't got on to the next reading book, you know at school. (Kay, Second Interview)

Before the birth of Joe, the family narrative for Kay’s family was laid out between her as a paediatrician and her husband a teacher. Reflecting on the life they now lead, they recognised that before Joe they were living the relatively stereotypical life their presumed social position suggested, looking forward to both having children and advancing in their
careers. Like other parents they could envisage being caught up in the increasing governmental and societal surveillance of child development and success, they wanted the right kind of labels of achievement for their children; on multiple levels they lived in a comfy and safe home. In their critique of the child development criteria aimed at both their non-disabled and disabled child and in their shift in career trajectories we see the agency they exercise, which both provides a space for them to reassess the values associated with their social position, while also being allowed by the resources generated by that social position. Their current rejection of universalising notions of development and anticipated abilities over the ‘normal’ life course hints at the importance of the present for parents (see Fisher and Goodley in press) and the scope families can find to redefine their social position and subjectivities. As Grosz (1999) reminds us: modernity’s long term memory of the past and deliberate plans for the future may be felt as oppressive and inappropriate when engaging with our daily lives. For many of us, emphasising the present, the social realities of disruption and the uncertainty of the future may support us in stepping outside of the parental rat race (at least for an hour or two).

Conclusion

There are areas within parents’ lives where they seek some form of certainty. They wish to have a medical diagnosis, follow medical procedures to treat their children and have some sense of what the future holds. Having a new baby or infant with a disability is unsettling, placing parents within new worlds of social discrimination and medical intervention and control. Certainty can provide a sense of control and stability. Yet, in seeking such things they do not do so without also recognising that certainty might limit them and create problems for the family. As they travel through medical and social worlds they see the costs of ‘gazing’ at their baby or infant only through the lens of medical categories and service procedures. Fortunately, they find places that allow their child to develop as a child and to find subjectivities outside the rubric of medical and social expectations. Their interaction with the certainty of diagnosis and treatment is informed by strategic agency on their part, which recognises that at some points working with the narrative of medical certainty or legal certainty may benefit their child. At other times, by challenging the benefits of treatments or exercises and by becoming disinterested in finding out the name that medical professionals seek, they make situated choices to limit their participation in activities that exist within a framework of predictive certainty. The least level of certainty they have is what the future holds, but for many parents this is no longer a source of anxiety, instead they embrace an immediate future they never planned for, which in an everyday way changes them in imaginative and uncertain ways.

It is possible to view the parents of our study as critical thinkers and actors that re-present and refine particular un/certainty theories. The parents blur modernist and postmodernist agendas. There are times when the nihilism of deconstruction is unhelpful. Using medical discourse is of course necessary to sort out the feeding tube of a child or to administer drugs in response to fits. A few moments later, however, these pragmatic parents are also engaged in processes of undermining labels, diagnoses and discourses associated with their children. They are both nomad and settler. They can enlighten social theory by highlighting that people's lives cross the academic neat divisions made between those
writers seeking to identify the world of uncertainty and play and those seeking to identify the world of certainty and material oppression. Research with such groups, positioned as marginalised and vulnerable, both shows the pressures and constraints such unequal and unjust conditions place on them, while also bringing to the fore the creativity and critical agency they bring to contexts where certainty is both sought and recognised as fictional.

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1 ‘Parents, Professionals and Disabled Babies: Identifying Enabling Care (RES-000-23-0129)” (http: www.shef.ac.uk/inclusive-education/disabledbabies/). The other people involved in the project are Dr Emma Clavering (Newcastle University), Dr Pamela Fisher (Sheffield University) and Dr Claire Tregaskis (Plymouth University).