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# The politics of autonomy in genetic testing of children

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## Abstract:

Current ethical guidelines for the genetic testing of children protect the 'child's future autonomy' from parental choices if there is no immediate medical benefit from testing. Drawing loosely on 'governmentality' as an analytics of power, we argue that ethical guidelines are symptomatic of a shift in the way that children are constituted as subjects and as potential citizens. For instance, the concept of autonomy has emerged as a liberal solution for the governance of genetic information: subjects are to be governed through their freedom and by enacting their lives through an ethic of choice. However, governmentality is at risk of missing some important tensions within the politics of childhood testing if it fails to analyse the authoritarian dimension of liberalism. The paternalistic character of ethical governance is not so much a confrontation between autonomy and medical authority, but a new kind of obligation between professionals and clients. In this paper, we consult empirical examples of interview data with medical professionals to examine the rhetorical construction of ethical dilemmas. Professional accounts reveal competing versions of autonomy and ambivalence about difficult and challenging interactions with parents and children. Our findings suggest that authoritarian and liberal practices are twin aspects of a practical rationality that seek to recruit the child's autonomy as a device for shaping adult decisions and producing future subjects who are self-sufficient in the management of their genetic risk.

## **Introduction:**

Advances in biomedicine have generated more rather than less tensions between choice and responsibility. These tensions are realised not only by individuals and families, but at the level of *political reason*, over the development of instruments for the government of populations. Experts in biomedicine, law, ethics, psychology, sociology, and so on, will deliberate the legal, ethical and social implications of technologies that may or may not optimise life and prevent future illness. In the field of human genetics rapid advances in genetic testing and screening have posed major challenges for concepts of governance and ethics. Predictive testing of presymptomatic adults, for instance, has raised serious concerns over privacy and confidentiality as well as having an uncertain impact on identity and subjectivity. The right to know or not to know one's genetic future combined with the tensions of responsibility and choice are characteristic of the problems of advanced liberal societies. And in the predictive testing of children, this is symptomized by acute debates about 'informed consent', the dominant solutions of which have been the preservation of the child's *future* autonomy.

In this chapter, we will explore how the concept of autonomy has emerged as a liberal solution for governing genetic services. In the first two sections of this paper, we will trace the way in which autonomy has appeared in relation to profound transformations of political rationalities, and numerous problematizations of medical authority. An historical account will offer a redescription of the circumstances in which autonomy occupies a key role in debates about childhood testing. Next, we describe our methodological framework and then present a rhetorical discourse analysis of professional interviews in the data analysis section. This is followed by a discussion of our findings: linking the rhetorical aspects of professional accounts with the contractual and regulatory aspects of autonomy.

## **Governmentality, liberalism and health**

In the governmentality literature, liberalism is often taken to mean the 'mentalities of rule' that invest in the hope of making subjects who do not need to be governed by others, but will govern themselves (Rose, 1996: 45). An analytics of government draws from neo-Foucauldian interpretations of 'political rationalities' and 'technologies of government', characterised by governmental programmes, practices and devices that accord a central place to individual liberty (Foucault, 1991; Gordon, 1991; Dean, 1991). This particular view of liberalism argues that individuals are governed *through* their freedom. Governmentality scholars attend to debates and strategies which delineate a general field for the 'conduct of conduct', a field comprised of heterogeneous authorities, subjects, problems and spaces. It does not offer a theory of power but a perspective that renders certain questions possible about 'the problems and problematizations through which 'being' is shaped in a thinkable and manageable form' (Rose, 1999: 22).

Such a view of government is no doubt helpful in diagnosing a profound reorganization of political power in liberal societies<sup>1</sup>. The term 'neo-liberalism' should not be understood as a neologism designating an epoch or an actual state-of-affairs, but an 'individuation of a multiplicity of attempts to rationalize the nature, means, ends, limits for the exercise of power

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<sup>1</sup> In keeping with liberal principles of limited government, the market provided the ideal mechanism for subjecting all aspects of conduct – decisions, strategies and goals – to a competitive model of freedom and prosperity. By the 1970's, neo-liberalism was not just oriented to 'the economy', but the creation of *a society* that was directed towards its existence. Gordon describes this innovation as the ability to bring into being 'the open space of the market and the artificial game of its competitive freedom as ... a possible new political legitimacy' (Gordon, 1991: 41).

and styles of governing, the instruments, techniques and practices to which they have become linked' (Rose, 1999: 28). To govern in an 'advanced' liberal, or 'neo-liberal', way describes an emergent strategy of giving programmatic coherence to the logics of the market. This would provide the basis of governing autonomous entities through installing new technologies for 'governing at a distance' (Rose and Miller, 1992: 173). An analytics of government therefore provides an important perspective with which to interrogate recent changes in the organization of healthcare.

There are three dimensions along which certain transformations of expertise have shaped the politics of health. Firstly, experts were transformed into knowledge workers as opposed to acting as functionaries of the state. The medicalization critiques of the 70s succeeded in not only questioning the hierarchy of medical authority, but directly confronting medical paternalism with patient autonomy (Szasz, 1970; Zola, 1972; Ilich, 1976; Buchanan, 1978). The old bureaucratic enclosures of healthcare were replaced by the instruments of business management: targets, audits and the empowerment of end-users. Health professionals would now provide 'information' in the form of counselling, risk-assessment and consultation for the promotion of self-government. The new relationship between medical experts and clients would no longer be 'organised through compulsion and planning but through acts of choice' (Rose, 1993: 296). Secondly, the social technologies of authorities and experts were autonomized and de-centralized. The devolution of central state power was assembled into a single network comprising provincial, local, municipal, and regional authorities. The enclosures of expertise and bureaucracy were penetrated and governed by new forms of accountability. Universities, hospitals, social services and charities were obliged to adopt practices of financial calculation, to translate practice into financial terms, and to restructure activities in terms of their cost-effectiveness (Rose, 1999). Decentralization and accountability would form twin strategies, promising more effective governance through faster response rates between authorities, experts and citizens (McGregor, 2001). Thirdly, political rationalities and social technologies would specify a new subject of government. The behaviour of individuals were refigured within an economic conception of purposive actions, strategic choices, and means-end rationales<sup>2</sup>. Following the breakdown of welfare systems, individuals were to engage in the private management of risk. They were to become 'prudential citizens', obliged to engage in the calculation of risk and the endless management of future uncertainties (O'Malley, 1992). Under this new form of government, citizenship is no longer a universal right conferred by the state but contingent to one's autonomy.

The twin strategies of responsabilization and autonomization were, after all, solutions to what was described as a 'crisis in healthcare'. By the late 70s, rising inflation and unmet consumer need served as preconditions for change. More disturbing for the medical fraternity was that society seemed to accuse healthcare professionals for being responsible for the crisis. Medical paternalism had paralyzed a system over which consumers felt they had no control. The obvious solution seemed to be the radical liberalization of medical authority. This has been accurately described by de Vries (1980, 1982) who argues that the growth in personal autonomy might eventually alleviate the crisis in healthcare. By advocating the rights of patients and consumers in the name of autonomy, bioethics would actually facilitate these programmes of liberalization. Before considering the role it played in governing genetic technology, it is necessary to trace the 'rediscovery' of autonomy within a certain reinterpretation of Immanuel Kant.

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<sup>2</sup> Gordon remarks how conceptions of *homo economicus* have changed from the figure who was 'untouchable by government' to the American neo-liberal model as thoroughly manipulated and perpetually responsive to modifications: 'Economic government here joins hands with behaviourism' (1991: 43).

### *The rediscovery of autonomy*

As is well known, Kant is the modern inventor of autonomy as moral authority (Dworkin, 1988; Hill, 1989; Herman 1993; Korsgaard, 1996; Schneewind, 1998). If liberalism was to become a promising reality it would require a conception of the subject who could *legislate* their own morality. Kantian autonomy presupposes enlightenment notions of Cartesian self-awareness and transcendental views of rational self-government. His moral programme would serve as the cornerstone of an emergent liberal society, one that would ascribe an essential moral identity to individuals, and universal duties and obligations to that of society. By establishing autonomy as the condition in which sovereignty becomes a property of individuals, Kant initiates a break with Western philosophy, and in doing so elaborates a framework of liberal society based on moral responsibility.

The interpretation of Kantian autonomy as self-determination was the peculiar invention of American bioethics. During the 60's and 70's, theologians, philosophers, doctors, and legal experts assembled in forums and committees to discuss the complex ethical and legal issues resulting from medical technology. Bioethics emerged from various problematizations about death and dying, human research, kidney dialysis, organ transplantation, genetic research and provided a critical intermediary between biomedicine and the public. Liberal intellectuals who turned their hand from 'civil rights to patient rights' employed the principle of autonomy to breach expert enclosures (Jonsen, 1998). Medical professionals were now accountable to an informed public who demanded greater choice in the delivery and quality of healthcare. Kantian morality provided the intellectual resources to mobilize a model of *individual sovereignty* that would underpin the logics of the market.

### **Molecular politics of the child**

Since the mid-80s, advances in molecular genetics have problematized legal, ethical and psychological aspects of personhood. The growth of personal autonomy in healthcare has led to the veritable expansion of technologies concerned with optimising the 'informed consent' of individuals, and to make rational and responsible choices about one's health. These developments have occurred alongside significant transformations of the children's rights, their increasing role within medical decision-making, and the increasing protection of their right and ability to act autonomously. In this section, we consider several key trajectories along which a molecular politics of the child can be traced.

Ethical concerns about predictive testing were first alerted by professionals when accurate tests for Huntington's disease (HD) were available (Craufurd and Harris, 1986). Characteristic of the so called 'new genetics', advances in molecular diagnostics literally outstripped developments in medical treatment. Presymptomatic individuals could be diagnosed *before* a suitable prognosis was offered (Weatherall, 1991). Studies in psychiatric morbidity had begun to document the deleterious effects of receiving an early diagnosis of HD (Kessler, 1987; Lam et al., 1988; Brandt et al., 1989), while problems of confidentiality, legal protection, and informed consent were reported by concerned professionals. Guidelines were established by the World Federation of Neurology in conjunction with the International Huntington's Association, and the United Kingdom Huntington's Disease Prediction Consortium (1989, 1990; Tyler and Morris, 1990). In many respects, HD would serve as an exemplar for the construction of ethical guidelines and reporting of peculiar cases<sup>3</sup>

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<sup>3</sup> Bloch and Hayden (1990) and Tyler et al. (1990) have cited cases where mothers had insisted on predictive testing, arguing that bonding with the child could only occur if their risk of HD was low. Morris et al. (1988) and Tyler (1988) have also documented cases where adoption agencies have claimed the right to request testing

(Boddington and Hogben, 2006). Given the complex nature of genetic risk, one of the early recommendations was that predictive testing be only available to those who have reached the 'age of majority', the partitioning of which set a precedence for later codes and guidelines around the world.

The rise of informed consent during the 80s also paralleled significant transformations in the ethical-legal rights of the child. In the United Kingdom, the famous ruling by the House of Lords in the *Gillick v West Norfolk and Wisbech Area Health Authority* (1985) highlighted the tensions between consumer-oriented healthcare and the traditional rights of parents. By ruling in favour of the Health Authority, a new legal precedence established a standard where children below the age of sixteen can be assessed in terms of their capacity to consent to their own medical treatment. 'Gillick competence' would extend the limits of the child's right to choose so long as they could demonstrate sufficient understanding and intelligence (De Cruz, 1987). The Children Act of 1989 also reinforced the view that children are no longer a 'thing in need of protection' but a legal person to whom rights are conferred (King and Piper, 1990). Children were now legally separate entities, while parents were contractually bound to promote their 'best interests' (Buchanan and Brock, 1989). These developments were not unique to the UK but followed a pattern of global governance. The United Nations Convention on the Rights of Children (1989) also ratified the wider participation of minors in their own welfare, and confirmed the global expansion towards promoting the child's self-governance.

By the early 90s, the diffusion of genetic testing for other disorders (e.g. Duchenne Muscular Dystrophy, Breast and ovarian cancer, cystic fibrosis) raised further problematizations and led to stronger calls for industry guidelines (Craufurd et al., 1990; Harper and Clarke, 1990; Geller and Holtzman, 1991; Holtzman, 1992). In the UK, the Clinical Genetics Society (CGS) commissioned a Working Party to specifically report on the genetic testing of children. A key recommendation of the report stated:

predictive testing for an adult onset disorder should generally not be undertaken if the child is healthy and there are no medical interventions established as useful that can be offered in the event of a positive test result. We would generally advise against such testing, unless there are clear cut and unusual arguments in favour [...] This respect for autonomy and confidentiality would entail the deferral of testing until the individual is either adult, or is able to appreciate not only the genetic facts of the matter but also the emotional and social consequences of the various possible test results (1994: 2).

In frameworks like these and the many others that followed, 'respect for autonomy' would form the central principle of ethical governance. Various instruments would be called upon to generate supporting evidence: ethical principles, legal judgements and attitude questionnaires. First, Kantian notions of biomedical ethics (see Beauchamp and Childress, 1984) would provide 'off the shelf' concepts focusing on individual aspects of autonomy, choice and informed consent. Second, medical professionals would consult legal judgements about whether genetic services were acting according to the welfare of the child and within the general principles of malpractice law<sup>4</sup>. Third, attitude surveys would measure the 'range of opinion' among publics and professionals. With their presumed objectivity, surveys would

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as part of their duty to inform prospective parents. In both cases the problematization of 'third parties' are presented as threats to the child's security and the new logics of citizenship.

<sup>4</sup> In Britain, there is a presumption that legal requirements are a reflection of developments in professional ethics.

provide effective means of eliciting from the population measures of relatively stable mental processes which are thought to predict behaviour (Rose, 1996).

After the CGS had published their guidelines, the Genetics Interest Group (GIG), a umbrella consumer group, were quick to criticize the recommendations. They claimed that the overall tone of the report was 'patronising to parents', it failed to recognise parental autonomy in issues of family support and seem to reflect professional anxieties about legal reprisals (Dalby, 1995). Others have criticised the medical profession's power in regulating who qualifies for service-provision (Sharpe, 1993). A similar view has been put forward by Michie (1996), who argues that parental access to childhood testing should be publicly debated rather than decided by the medical profession. The restriction of genetic services on the presumption that genetic testing is harmful to children is paternalistic.

Robertson and Savulescu (2001) have also challenged the paternalistic approach of the medical profession. They argue there is little evidence to support the medical view that childhood testing creates a 'burden of certainty' resulting in severe psychological harm. Their main focus is to re-examine Clarke and Flinter's (1996) central claim that predictive testing breaches the child's 'future autonomy'. They argue that parental decisions do not *necessarily* violate the child's future autonomy. Just as personal autonomy asserts the individual's right to legislate their own affairs, Robertson and Savulescu defend *parental autonomy* as having a privileged and intimate connection with children. The presumed psychosocial benefits of testing enable parents to remove the burden of uncertainty. Others (Duncan, 2004; Duncan and Delatycki, 2006; Duncan et al., 2007) cite a modicum of empirical evidence supporting the view that testing has psychosocial benefits for 'young people'.

The molecular politics of testing raises numerous concerns about the rights and responsibilities of children who are to be contracted into circuits of medical decision-making, treated as legally separate entities from their parents, and endowed with capacities to make their own rational choices. In the context of these debates there seems to be an assumption that children need to be protected from their parents. Consumer groups and various advocates have contested this view by defending the role of parental autonomy within medical decision-making. The pessimism and caution with which the medical fraternity have responded to the genetic testing of children is perhaps indicative of the legacy of eugenics that still casts a shadow over these debates.

#### *Choice, responsibility and paternalism*

At the heart of this ethopolitics of testing is the issue of *whose* autonomy is sovereign in matters of healthcare, especially when the genetic risk is treated as exceptional to other kinds of medical information (Murray, 1997). The paternalistic dimension of medical authority assumes the role of adjudicator between competing versions of autonomy. On one side, we have a version of 'genetic responsibility' (Novas and Rose, 2000) where autonomy forms part of a humanist model of responsible selfhood – the active citizen enjoined to make prudent choices in relation to oneself and one's future. On the other, we have the relational and benign responsibility of parental autonomy which, through genetic testing, seeks to remove the psychosocial burden of uncertainty. According to the medical profession this view is misguided because it fails to consider the child's future autonomy. Networks of experts from law, psychology, philosophy and the social sciences provide medical paternalism with tools for restricting parental rights, while conferring an ethic of private choice to the child. Here, authoritarianism is anxious to *delegate sovereign decisions* to individuals who, by choosing a test, may also be choosing a genetic identity.

Medical authoritarianism should not be confused with the old confrontations between paternalism and autonomy, but rather those now arising from choice and responsibility (Chadwick, 1999). The paternalistic dimension of medical expertise is less concerned with interfering with a person's liberty than inducing liberty as a mutual obligation of care. In the 'pastoral technology' (Foucault, 1981) of psychosocial genetic counselling, autonomy is an essential precondition of the clinical consultation. The nondirective ethos of the profession, while criticized by many (Petersen, 1999; Williams et al., 2001), seeks to create an interpersonal space of shared decision-making, whereby counsellors facilitate reflection and planning future action (Hallowell, 1999; Sarangi and Clarke, 2002; Pilnick, 2002). In the domain of childhood testing, as we have seen, pastoral power seeks to supplant the authority of parental autonomy and prioritize the making of potential citizens who are *obliged* to choose in relation to their genetic risk.

### **Present study**

Participants were recruited from paediatric and genetic services in Cardiff (Wales) and London. Both convenience and snowball sampling were used to contact professionals involved in genetic testing of children. Semi-structured interviews (n=20) were conducted with paediatricians (n=10), clinical geneticists (n=2), and genetic counsellors (n=8), asking specifically to provide retrospective accounts of difficult or challenging cases involving the testing of children. The interviewees were also asked to give explanations of their ethical orientation about matters relating to the competence and maturity of children, the concept of autonomy, the ethical differences surrounding predictive and carrier testing, and the difficulties of practicing nondirective counselling.

A broad thematic analysis was conducted on the transcripts using an iterative technique of close reading, note-taking and coding. Research interviews were treated as an 'artefact' of a social encounter, a joint accomplishment of the interviewer and respondent (Dingwall, 1997: 56). In this sense, interviews were not analysed as the representation of 'content' or 'reality' that exists beyond the interview, but as an occasioned activity for the production and elicitation of 'accounts'. Accounts are action-oriented descriptions and explanations that encompass a wide range of rhetorical purposes such as justifying, excusing, defending and persuading (Antaki, 1994). The coding criteria of accounts were based on the interactional aspects of 'reporting troubles' (Morris, 1994) vis-à-vis heritable risk and childhood testing. Accounts of professional ethical dilemmas were identified via categorisations of conduct and reported tensions between different participants (e.g. mothers, fathers, practitioners, children, etc.). Different thematic aspects of our sub-corpus emphasised different characters and events around which ethical dilemmas were constructed. After coding and checking, a total of (n=26) extracts were compiled into a sub-corpus for more detailed analysis.

From our sub-corpus, we selected the most illustrative accounts under each theme for rhetorical discourse analysis (Arribas-Ayllon, Sarangi and Clarke, 2008a; 2008b; see Arribas-Ayllon, Sarangi and Clarke, forthcoming, for an alternative analysis of the corpus). Extracts were significant in the way power relations were discursively and rhetorically encoded to reconstruct tensions between professionals, parents and children in clinical and counselling scenarios. This entailed identifying and explaining a range of devices through which ethical/moral explanations are constructed: contrast, reported speech, constructed dialogue, character and event work. Contrast structures (Smith, 1978) are effective ways of not only categorising behaviour and identity, but also establishing different versions of events. Constructed dialogue, or 'reported speech', is one device widely used in accounts to recruit



voices and authenticate different versions of events. Character work is strategically deployed as moral descriptions/categorisations of conduct which facilitate ethical perspective-taking. Similarly, event work offers a re-interpretation of temporal (past/future) events to suit the speaker's current concerns.

### **Data analysis**

For the purpose of this paper, we identified two analytic themes which exemplify the dilemmas of childhood testing: *parental autonomy versus child's autonomy* and *eliciting the child's autonomy*. Each theme foregrounds the professionals' reconstruction of characters and events in which the child's autonomy is problematised and constituted as an object of preservation and calculation.

#### *Parental autonomy versus child's autonomy*

The most commonly cited problem amongst professionals were requests for testing by parents. This occurred in two kinds of scenarios: parental requests for adult testing with the purpose of (not) disclosing risk to children or simply parental requests for childhood testing. In the case of the former, genetic counsellors, in particular, expressed concern over whether parents had 'thought through' the consequences of their request, especially if they intended to disclose this risk to their children. The following extract is indicative of the counsellor's (GC) concerns about the child in the context of risk for Huntington's Disease:

#### **Extract 1**

1. **GC:** One of the classic things is that people will come and say, well um I need to
2. know for the sake of their children, which is a very good reason to know but
3. actually-
4. **R:** Is that a very common reason?
5. **GC:** Yup, very common reason, I need to know because- for the sake of my children
6. because I need to know whether or not I need to tell them about Huntington's disease.
7. **R:** Right.
8. **GC:** Um (.) now, that's fine but (.) the thing is, they're are doing a test on themselves so
9. they- it will have an effect on them- whatever.
10. **R:** Absolutely yeah.
11. **GC:** um and b) the first thing I ask is well a) do your children know about the risk of
12. Huntington's in the family, and they might say yes or no and if they do know about it
13. well what are their thoughts about it would they want to know themselves.
14. **R:** Yeah.
15. **GC:** Um because if they don't then, why would you want to ask for a test because they're
16. not interested.
17. **R:** Mm.
18. **GC:** And things like that so we sort of question it around that and, I mean sometimes
19. perceive it as trying to put them off we're just sort of I guess testing out their, their
20. thinking.

The counsellor orients our attention to the routine and characteristic ('classic') scenario of which we are about to hear (lines 1-3). The voice of the parent is heard via constructed dialogue casting a request for testing in terms of 'my children'. The counsellor's concession (line 2, 'which is a very good reason'), while displaying empathy and agreement, prefigures a reprise marker which will counter parental request for testing ('but actually-'). After R's probe for confirmation (line 4), the reprise marker returns (line 8, 'that's fine but') where GC seeks to establish that adult testing 'will have an effect on the [child]'. The researcher's affirmative response at line 10 is complicit in producing an account of parental deficit as in failing to consider the child's point of view. By recruiting the child's voice (lines 12-13), the counsellor uses hypothetical talk ('if they do know about it well what are their thoughts about

it') to frame the possibility that the child might not want to know 'about the risk of Huntington's in the family'. This provides justification for why counsellors ought to monitor and test parental rationales for testing. Also interesting is how parental resistance is encoded (lines 18-19, 'sometimes they perceive it as trying to put them off') in relation to these questioning procedures.

The most frequently cited dilemmas were parental requests for childhood testing. Accounts of this kind were characterised by a three-party-tension (professional-parents-child), where professionals assumed the role of advocate for the child's autonomy. A key element of these accounts were the methods of contrasting the child's autonomy with parental autonomy, and routinely describing the motivations that *drive* parental requests for testing. In the account below, a genetic counsellor (GC) is describing the intellectual debate and the clinical experiences that have shaped her own 'ethical views' about testing children:

### Extract 2

1. **GC:** So his [Julian Savulescu] views to me were very sort intellectualised, rational
2. sort of approach, that went along the lines of well parents make all sorts of
3. decisions for children, this is just another decision you know they decide what-
4. school- you know they make decisions that have, an impact on that person's
5. whole life.
6. **R:** Mm hmm.
7. **GC:** Like which school they'll go to, and (.) that parents are perfectly capable they
8. know what's best for their children they're perfectly capable of making that
9. decision (.) and so therefore testing of children (.) should be allowed.
10. **R:** Mm hmm.
11. **GC:** And (.) that didn't- well (.) I'm not saying that parents aren't the best people to
12. make decisions for children (.) the logic and (.) what I saw happen- it just- his
13. stance just didn't fit with what I saw in clinical practice (.) which was, some
14. parents asking and (.) this is all in a cancer context, that I've had those
15. experiences (.) some parents sort of asking about children, when they find out
16. that they- that their cancer was due to (.) an inherited cause (.) asking, well
17. can I have my children tested? And when we'd say (.) that's not usual because a
18. lot of people choose not to know we think people should wait until they're older,
19. um to make those choices themselves because not everybody chooses to have
20. this information (.) most people kind of go, oh yeah, okay, that makes sense and
21. (.) a very few, just a handful, of people (.) start getting quite annoyed about that
22. angry, and start really focusing on (.) wanting (.) everything seems to become
23. focused on wanting this child tested.

The counsellor is contrasting her own ethical position with that of 'Julian Savulescu', a bioethicist, who controversially argues in favour of parental autonomy (cf. Robertson and Savulescu, 2001). His views are characterised as 'very sort of intellectualised, rational sort of approach' (lines 2-3), which does some rather subtle rhetorical work. She is inferring that Savulescu's defence of parental autonomy is *excessively* rationalised and is not a grounded perspective. This contrast between rationalism and empiricism appears later in the account (cf. line 13). GC rehearses Savulescu's argument (lines 2-9), which not only demonstrates her awareness of the debate, but subtly navigates her own moral orientation towards parental decisions. Saying 'this is *just* another decision' (line 3) implies that such arguments relativize decisions *about genetics* as merely any other kind of parental decisions: 'like which school they'll go to' (line 7).

GC counters this argument with some difficulty. In line 11, she hesitantly pauses and the dispreferred marker 'well' betrays ambivalence. The defensive 'I'm not saying that parents

aren't the best people to make decisions for children' seems to anticipate potential disagreement. The change in footing (line 13, 'his stance just didn't fit with what I saw in clinical practice') attempts to undercut the rationalist view by suggesting that 'the logic' did not square with 'clinical experience'. In what follows, GC must demonstrate that parental autonomy is *evidently* problematic, which is accomplished by reconstructing a scenario of terminal hereditary cancer. The voice of the parent is heard asking for a test via constructed dialogue (lines 16-17), while the counsellor can be heard explaining this as a departure from what normally occurs ('not usual', 'a lot of people choose not to know', 'not everybody chooses'). While most parents accept the counsellor's discouragement only a small minority 'start getting quite annoyed'. This is upgraded to anger and obsession (line 22, 'they start really focusing on (...) wanting') casting parental persistence as excessive and unwarranted.

Notions of character are also instrumental in the Kantian account of children being treated as a 'means to an end'. In Extract 3, the same counsellor uses this argument to useful effect. GC is narrating a 'second referral' case involving a woman with Familial Adenomatous Polyposis (FAP) who was refused testing when she 'came in wanting all five of her children tested'.

### Extract 3

1. **GC:** So she'd become very cemented in this I've got to have this test, and- (...) but she
2. was also to her credit quite upfront about her reasons for that (...) and it was very
3. much for herself she has Desmoid disease.
- [3 lines omitted]
7. the outlook for her wasn't particularly good, and so she was saying I want to
8. know (...) what my children have, um (...) so that I can die in peace basically, and
9. (...) you know because I- it was for her anxiety and her worries about the future
10. and wanting to know what was going to happen to her children.
11. **R:** Yeah.
12. **GC:** And that (...) hhh- I think there are some people Julian might argue this that
13. actually it's a reasonable reason of parental anxiety as a reason to (...) offer
14. children, have children tested because, if the parental anxiety is relieved that's
15. going to improve, the lives of the children (...) or if the parental anxiety is not
16. relieved, we don't know the effects on the children.
17. **R:** Mm.
18. **GC:** And to me, in a way (...) that seems to be treating children as a means to an end
19. and the end is the relief of parental anxiety and testing the children (...) is a means
20. rather than being the end in itself.

GC's narration forms the basis of a generalized, scripted account of what we can expect from excessive parental autonomy. Character work indexes the woman's rigid determination as an extreme case (line 1, 'very cemented') who is heard hypothetically demanding 'I've got to have this test'. The concession (line 2, 'to her credit') signals a balanced and fair assessment of the woman's selfish motivations. Event work provides adequate justification for the woman's concerns: 'I want to know (...) what my children have, um (...) so that I can die in peace basically' (line 8), but is contrasted by her motivations, which, as it transpires, really seek to assuage her own fears. Parental autonomy is cast as excessive and pathological, driven by anxiety rather than the best interests of the children.

In lines 12-16, GC provides a contrasting view of childhood testing by revisiting an earlier argument in favour of parental autonomy (cf. Extract 2). Here, the utilitarian claim that 'it's a reasonable reason' to test children argues that reducing parental anxiety will 'improve the lives of the children'. Of course the other alternative is where 'parental anxiety is not

relieved' because the test is positive. But there is no empirical evidence to suggest that testing is harmful to children (line 16). This is contrasted with a deontological view: testing children to relieve parental anxiety 'seems to be treating children as a means to an end' (line 18). Interactionally speaking, this Kantian view has the effect of arguing that children need to be protected from their parents. This reflects the view of current ethical guidelines.

So far, we have examined cases where characters are seeking to relieve adult anxiety, particularly when a terminally ill parent is involved. Next, we consider the reconstruction of a 'difficult' case in which parents *demand* testing and are quite resistant to counselling. The genetic consultant (GC) begins by describing a recent case involving carrier testing of two young children at risk of Cystic Fibrosis (CF).

#### Extract 4

1. **GC:** I had one recently actually where a (.) couple have got a child with cystic
2. fibrosis (.) and they have two children of, I don't know let's say six and eight,
3. and the (.) father is adamant that these two children should be, um tested- have
4. carrier testing performed, um (.) and he's in a- he's a very aggressive (.) um
5. pushy difficult man, and who's- and what he's done is, he's in a- an extreme
6. state of anxiety himself mainly because someone said no- well we haven't said
7. no to him, we've just said well (.) you know how about the principles of this
8. thing let's go through the whole idea of why you're doing it, and he doesn't like
9. that, doesn't want (.) and so he's rushed around you know, banging like a sort of
10. bee in a box, banging around, and um (.) the pragmatic decision that we have
11. made, is that um, if he wants that testing done, we would rather (.) he went
12. through that testing procedure in a supportive way where we can (.) discuss the
13. issues and that sort of thing, although he just doesn't- he doesn't want to engage,
14. so we finished up with- he's actually (.) come steaming down- he's a [place]
15. patient, come steaming down here and presented himself at clinic demanding
16. that these children have carrier testing, and that that's a very um diff- difficult
17. one because it um (.)
18. **R:** Simply because he's demanding it?
19. **GC:** Um
20. **R:** It makes it awkward for you or-?
21. **GC:** I think, not that he's demanding it so much, that it's- that it's apparent, maybe
22. it's because he's not doing what we think he should.
23. **R:** Right.
24. **GC:** Maybe it is as simple as that.
25. **R:** Right.
26. **GC:** But it's, I don't think he's (.) taken time to recognise (.) um looked at himself
27. and his need for doing it, it's a huge control issue.
28. **R:** Yes I see.
29. **GC:** And um (.) and why is that important to me? And I don't know because it is a bit
30. of a struggle, there's part of me that wants him to recognise, that what he's
31. doing, actually is about control, it's about his own anxiety and it actually isn't
32. about the benefit of the children, is my belief, now I might be wrong.

After quickly describing the clinical context, GC builds the character of the father who is demanding carrier testing for his two healthy children. The index to 'adamant' encodes the father's inflexibility and persistence which, as we will see, has an important bearing on the narration of events. Character work persuades the listener/reader that the father's inflexibility is not episodic, but an enduring personality disposition (lines 4-5, 'very aggressive ... pushy difficult man'). Before GC can narrate the key events of the encounter (line 5, 'and what he's done is'), more work is performed to build the father's 'extreme state of anxiety'. The psychological assessment is effective in casting him as *seriously irrational*, which is linked to an earlier refusal of services (line 6, 'someone [has] said no'). This is quickly repaired to

sound less directive ('well we haven't said no to him') and reformulated in counselling talk ('we've just said ... how about the principles of this thing let's go through...'), the resistance to which is explicitly encoded ('and he doesn't like that'). It is also worth noting that the father has evidently heard '*let's talk about the ethics of childhood testing*' as meaning '*no, you can't have your children tested*'.

Lines 9-10 continue to frame the father's irrational conduct ('and so he's rushed around ... banging like a sort of bee in a box'), which is contrasted with the 'pragmatic' advice of the counselling service. GC frames the rational alternative as not refusing testing, but asking the father to participate in 'the testing procedure in a supportive way' (line 12). The professional view offers opportunities for rational and cooperative discussion, which to refuse would be manifestly irrational and uncooperative. The rising tension of the father 'demanding' carrier testing also produces ambivalence (lines 16-17, 'that's a very diff- difficult one'). R probes the ambivalence, inviting a subjective account of the 'difficulty'. This is denied in favour of a speculative explanation ('maybe...') of the father's non-compliance. GC's 'simple' explanation is the practical difficulty of counselling parents who place their own needs above their children. In asking herself 'and why is that important to me?', GC actually performs self-examination, presenting a professional self who is divided ('there's part of me...') and ambivalent ('I don't know'). The 'struggle' (line 30) she refers to is the practical difficulty of aligning parental autonomy with the perspective of the child. Stating 'and it *actually* isn't about the benefit of the children' (lines 31-32) claims to *know* the father's real motivations (i.e. 'anxiety' and 'control') that are concealed by the best interests of the child. Tokens and concessions such as 'my belief' and 'now I might be wrong' while performing ambivalence, also mitigate the paternalistic view.

So we have examined how professionals have a variety of discursive resources at their disposal to problematise parental autonomy and respectively advocate for the child. Parents are depicted as having failed to calculate the consequences of childhood testing, or having failed to recognise their own needs and concerns for requesting a test, and; at the very worst, they seem to treat their children as a means to an end. Parents who do not comply with counselling protocols and procedures are routinely described as excessive, anxious, inflexible, and selfish. These interactional difficulties between parents and experts also encode ambivalence and paternalism, issues of power that we will return to in the discussion/conclusion.

### *Eliciting the child's autonomy*

So we have seen how testing is problematised when parental autonomy threatens to dominate the best interests of the child. In this section, we consider examples in which the autonomy of the child presents certain clinical challenges for professionals. Some professionals described the difficulty of eliciting informed consent from children who fell somewhere between the category of 'minor' and 'adolescent'. Counselling at this grey zone of autonomy required novel techniques of assessing competence and maturity or inducing forethought and prudence among minors.

While some professionals believed that age was not a reliable index of competence, most voiced concerns that displays of informed consent by minors might in fact be adult decisions. These acts of 'ventriloquism', where parental autonomy is enacted *through* the child, were raised when professionals were opposed to testing. However, when all the adults (i.e. both parents and professionals) have agreed that childhood testing is beneficial then informed

consent is treated as a 'means to an end'. This is the view cautiously implied by one paediatric endocrinologist (P):

**Extract 5**

1. **P:** We saw a family, the father has MEN1 and they found the gene for him, he's got
2. the RET gene (.) and we saw the son and daughter recently to discuss with them,
3. screening (.) and in fact, interestingly enough, the parents very much wanted
4. them to be screened, the girl was about 14, the boy was about 12 (.) the children
5. themselves agreed to have it done, although I'm not sure they really had a
6. complete understanding of what it was all about, but [genetic consultant] was
7. very keen to screen them (.) and, of course, they've both turned out to be
8. positive, and I've yet to see them again now because now we need to go through
9. with them-
10. **R:** So [genetic consultant] was keen to screen them?
11. **P:** Yes.
12. **R:** Okay.
13. **P:** Because of the outcome of amnio, if you know they carry the gene then you can
14. screen them for the endocrine disorders and you can treat them early (.) so that
15. was the rationale behind it, and the current recommendations are that you should
16. start doing the biochemical screening from the age of 10
- [four lines omitted]
20. so the parents were very keen to screen, and I think they- the children just
21. agreed that that was okay (.) but I'm not- you know, it was the first time I'd met
22. them, so difficult to know what their complete understanding was.

P is reconstructing the clinical aspects of a case involving two children at risk of Multiple Endocrine Neoplasia Type 1 (MEN1), an autosomal dominant condition predisposing to tumours. Event work establishes that 'the son and daughter' had recently discussed the possibility of genetic testing. The reference to 'interestingly enough' orients our attention to the autonomy of the parents who 'very much wanted them screened' (lines 3-4). Describing the age of the children also foregrounds their potential autonomy as eligible participants in the clinical discussion. Their agreement to testing is immediately contrasted with P's ambivalence ('I'm not sure') as to whether they understood what they were consenting to (note how the extreme formulation 'complete understanding' is sufficiently vague to warrant interpretation). The contrast that follows is interesting ('but [genetic consultant] was very keen to screen them') which implies that despite P's uncertainty and the children's dubious consent, the genetic consultant sanctioned the testing. The marker 'of course' does some rhetorical work to justify (post hoc) that the decision was a sound one because 'both turned out to be positive' (lines 8-9).

In line 10, R is seeking confirmation about the genetic consultant's interest in testing, which warrants an account about why genetic services would be 'keen' to test the children. That an account is indeed warranted is confirmed in line 13, when P begins: 'because...'. He is explaining that if children carry the gene then they should begin regular 'biomedical screening' which can lead to better management of the symptoms. Given that useful medical interventions may arise from genetic testing, P reiterates that 'the parents were very keen to screen' (line 20). Unlike the kind of character work we witnessed in the previous theme, here the framing of parental demand is considered justified and normal. P continues by contrasting this scenario of adult consensus with the point of view of the children who 'just agreed that that was okay' (lines 20-21), again, inferring that their autonomous consent was figurative rather than instrumental. This inference is mitigated in the last two lines, indicating that P cannot be certain that the children were pushed into testing.

In the context of decision-making, when professionals discussed the child's autonomy they often invoked psychological notions of *capacity*. Most were uncertain about when minors begin to demonstrate this capacity, some believed it could occur before the age of 16 or 18 while others stated that even some adults struggled to engage in abstract forethought. One genetic counsellor contrasted 'the thirty-five-year-old' with 'the adolescent' to argue that adults could be rigid in their thinking and 'locked in one particular view'. Adolescents, on the other hand, could be more open to perspective-taking, but some had not yet developed 'the capacity for abstract thought'. Rather than adhering to a smooth and linear developmental model of moral reasoning, professionals seemed to use contrasting discursive exemplars – 'the 35-year-old', 'the adolescent', 'the 12-year-old', etc. – to account for the variability of competence. Below, a respiratory paediatrician (P) uses the example of 'the 8-year-old' to illustrate some of the ethico-moral difficulties of deciding who is or is not competent:

#### Extract 6

1. **R:** In the literature it's quite common to cite the idea of autonomy, that the
  2. autonomy of the child is something that has become an object of preservation, or
  3. at least a benchmark from which we can gauge whether a child is competent or
  4. mature enough, what is your understanding of autonomy?
  5. **P:** You know, I would argue that I think children are autonomous pretty much from
  6. a few weeks of age when they've got their own personality.
- [two lines omitted]
9. but I would argue that the child is its own person from early age and most of the
  10. time they're influenced by their parents, but I think one of the paediatrician's
  11. roles is to be an advocate and to protect the child against perhaps the parents,
  12. and perhaps not necessarily malevolent but perhaps unrealistic expectations and
  13. wishes upon that child (.) and so I think the parents may be desperate for an 8
  14. year-old to have the test, the 8 year-old may tell you that it wants to have the
  15. test, but actually it's difficult to know is that the 8 year-old speaking or is that
  16. the parent speaking? And, you know, most 8 year-olds are affected by their
  17. parents and so- but, coming back to, say, Gillick competence, I think if you say,
  18. do you think this child is Gillick competent? Which is a real, you know,
  19. completely subjective assessment, and you could argue, we're doctors, we're
  20. playing God, we may keep saying, you're old enough to decide this, you're not
  21. (.) but I think we've always done that and we've always tried to do that in a
  22. beneficial way, and that may be patronising and it may be paternalistic, but I
  23. think we do still have the child's interests at the core (.) and I think, as
  24. paediatricians, certainly as a paediatrician, I feel strongly that it is part of my
  25. remit and role to try and look at it from the child's perspective, not- child first
  26. then the family – but not just from the parents' perspective.

R's question is orienting to a presumably 'common' version of autonomy which serves as the basis for assessing 'whether the child is competent or mature'. In this respect, a psychological account of autonomy is warranted. P responds to this invitation by offering a description of the autonomous child in the language of development ('a few weeks of age') and personhood ('personality'): autonomy is the emergence of an independent person (line 9, 'the child is its own person from early age'), and not necessarily a phase of adult-like capacity.

Through a series of contrast structures ('but'), P begins to problematise the child-parent relationship in order to justify the protectionist role of the medical profession. A humanist account of autonomy foregrounds the individuality of the child, while casting the parents as a mere background influence (line 10). In constructing this *unilateral* relationship between parents and child, P can now frame 'the paediatrician's role' as an 'advocate' of the child (line 11). The reference to 'protect the child against the parents' explicitly frames the

potential for abuse, while the downgrading of 'malevolent' to 'unrealistic expectations' is also explicit in promoting child protection. Furthermore, the desperation of parents (line 13) in seeking testing is similar to the excessive irrationality that we examined in the previous theme. The utility of the '8-year-old' as a device is illustrative of the difficulty of knowing whether *the child* is speaking or whether the parents are speaking *through* the child (lines 15-16).

P changes footing in line 17, orienting to an earlier discussion about applying 'Gillick competence'. In describing it as a 'completely subjective assessment', P is not undermining its validity as a clinical instrument but foregrounding a different kind of problem regarding expertise and authority. The device 'and you could argue' encodes the voice of an antagonist who explicitly disputes the expertise of the medical profession. P claims that 'we've *always* done that and we've *always* tried to do that in a beneficial way' (lines 21-22) the extreme formulation of which seeks to justify and convince that the medical profession is, historically speaking, a benevolent authority. In stating 'that may be patronising and ... paternalistic', P is anticipating further criticism, which is neutralised by the claim: 'we do still have the child's interests at the core' (line 23). The authority to discriminate who is and is not competent, while intrusive, is justified on the grounds of medical benevolence. P explicitly defends the paediatricians' right to exercise their authority by virtue of considering 'the child's perspective' (line 26).

By using the 8-year-old child as a model for discussion, P reconstructs the three-party-tension of childhood testing to defend the paediatricians' authority in protecting and assessing the autonomy of children. This is done by casting the minor as a psychological subject in their own right and by problematising the presumably unequal and unilateral relations between parents and children.

However arbitrary the timing, the point at which the autonomous child begins to enter clinical discussions was described by many professionals as a difficult and delicate procedure. The professional and emotional investment of eliciting the child's autonomy in medical disclosure and decision-making was significant and, for some professionals, accounted for as a 'proud' success of counselling. One of the genetic consultants we examined earlier (see Extract 4) described a case involving a '13-year-old girl who had a mosaic karyotype' for Turner Syndrome: a chromosomal condition that affects development in females. The voice of the autonomous child can be heard demanding 'I want to know what's going on' as both the consultant and a paediatrician perform the complex disclosure in front of the parents. In describing this case, the consultant conveys her pride with the way in which the autonomous child has claimed 'ownership' of the genetic information, information that effectively constitutes a genetic identity.

The notion of 'holding' genetic information until parents and/or children are ready to 'own' it was accounted for as a professional responsibility. Good counselling is the practice of controlling the disclosure of information in such ways that *responsibilize* individuals and families. However, in the case of childhood testing, who tells and when becomes an issue marked by professional doubt and paternalism. It is about such difficulties that the genetic consultant (GC) is explaining below:

#### Extract 7

1. **GC:** So you sort of hold it [information] and say, you know, this is what it is- and this
2. is (.) what we're talking about and actually it's yours, not mine, you know, it's
3. your information not mine, and that's um (.) and that can be quite hard- and



4. sometimes (.) you know you worry have I- have I not given it all back because
5. it does actually belong to them and- you know, you have to- I think sometimes
6. the patronising thing, where you um (.) or paternalistic thing sometimes where
7. you think don't worry I'll look after this for you, you just go off and do your
8. own thing, and you sometimes wonder have I really (.) demonstrated that this is
9. their information, this is about them? And when you've got a child in front of
10. you, you know, that's- that's more difficult again (.) and often- and the other
11. side of that is you see, if you make an agreement with a parent, that you're not
12. going to test a child, for something, for all the best reasons, you then have to
13. have some sort of contract (.) too strong a word but, where who is going to give
14. that information to that child at the right time? Do I write out of the blue to the
15. child and say oh, by the way, or do you rely upon the parent who may not have
16. that vocabulary or what do you do? And- and that's something I (.) you know (.)
17. um I haven't sorted out yet about the best way to do it (.) um (.) but its- you
18. know you have to name it and say look, in ten years time, when they can make
19. deductive decisions or whatever.

GC uses constructed hypothetical talk ('and say...') to rehearse a counselling scenario in which ownership of information is being transferred to the family ('actually it's yours, not mine'). The adverbial 'actually' draws attention to the novel contrast that the information is specifically *for* the family. What is inferred is that the family have to somehow live with this genetic responsibility: 'and that can be quite hard'. In line 4, GC conveys the benevolence of the professional who 'worries' (seemingly in her own time) about whether this *transference* has been properly completed (line 4, 'have I not given it all back?'). The 'patronising ... or paternalistic thing' describes the problem of whether delaying information (line 7, 'don't worry I'll look after this for you'), while evidently benevolent, actually fails to responsabilize the family. This is performed in a self-interrogative voice (lines 8-9, 'and you sometimes wonder have I really demonstrated'), which builds the reflexive and compassionate position of the speaker.

These difficulties are exacerbated when 'you've got a child in front of you' because they may not be in a position to 'own' information about complex risk. GC's discursive concerns are about *who* controls disclosure in the future. She explains that even when 'an agreement with a parent' is made not to test the child (note how *not doing* something for the child warrants an account: 'for all the best reasons') some kind of obligation is required ('contract' is mitigated as sounding too authoritarian) to ensure that the child is informed about their risk 'at the right time'. The possibilities for disclosure are formulated as rhetorical questions (lines 14-15, 'Do I write out of the blue ... do you rely upon the parent'), which convey calculation and ambivalence. In casting 'the parent who may not have the vocabulary' as the weaker option suggests that professionals are justified in controlling prospective risk communication. Though she is uncertain about 'the best way to do it', GC encodes a directive voice ('*you have to name it and say look*') to argue that risk communication should occur 'when [the child] can make deductive decisions'.

What is implicit to the consultant's account of children claiming ownership of genetic information is that autonomy – the capacity to make deductive decisions – is an essential precondition for genetic responsibility. Autonomy enjoins the child into new circuits of obligation for the calculation and management of their genetic risk.

## Discussion

We have argued that an analytics of government provides a useful perspective to explore the genetic testing of children as a problematic comprising certain mentalities, technologies, and

strategies of rule. The emergence of Kantian autonomy as 'self-determination', for instance, has provided strong ethical and moral justifications to preserve and protect a particular liberal conception of self-government. It is no coincidence that Kantian interpretations of autonomy appeared as healthcare was opening up to the logics of the market and the choices of the consumer. Contracting the autonomy of purportedly rational individuals would provide one important solution for alleviating the crisis of healthcare. Others have also noted (Armstrong, 1984) that medicine has increasingly constituted the patient as an active subject: 'one who must play their part in the game of cure' (Novas and Rose, 2000: 489). In short, bioethical conceptions of autonomy are the peculiar invention of American neo-liberalism.

In the current climate of genetic governance, medical professionals have been anxious to contract patient autonomy to share as much of the burden of responsibility for calculating genetic risk. Professionals' concerns about testing are informed by a rather pessimistic view of genetic knowledge. Firstly, the 'molecular' basis of testing is cast as somehow exceptional to, and more serious than, other kinds of medical testing. Secondly, the predictive, familial and essentializing aspects of genetic information are thought sufficient to increase discrimination and domination. Thirdly, there is a presumption that the predictive nature of genetic information may create a form of fatalism that is psychosocially harmful to individuals. These views have much in common with the geneticization thesis (Lippman, 1988), which argues that the objectifying aspects of genetic information undermines the core values of liberal humanism: free will, intentionality, responsibility, etc.

Healthcare is no longer characterised by explicit confrontations between paternalism and autonomy, but rather tensions arising between choice and responsibility (cf. Chadwick, 1999). In the molecular politics of childhood testing these issues are exacerbated precisely because children cannot participate in this game of active and responsible citizenship. Since the 80s, however, there has been a general shift towards the construction of children as the bearer of rights, as 'proto-citizens', who ought to be considered capable of making decisions in relation to their own health and welfare. Here, the concept of autonomy plays a central role in ethical guidelines and discussions where professionals are anxious to protect children from parental requests for genetic information. The implicit or explicit assumption is that parents somehow ignore or underestimate the deleterious effects of geneticization; that they seek genetic testing as a means of eliminating their own fears and uncertainty of risk.

In the context of the research interview, these tensions were jointly produced by contrasting competing versions of autonomy. At the rhetorical level, professionals would describe the motivational and intentional aspects of parental conduct as driving these professional dilemmas. For instance, script formulations of what *usually* occur in consultations convey the exceptional and extreme nature of parental requests, while professionals recruit the perspective of the child as a powerful device for shaping parental decisions. These scenarios were accounted for by either foregrounding the child's autonomy as a moral right – as a decision that children *ought* to make for themselves – or by foregrounding the possibility of psychosocial harm from inappropriate testing and disclosure. Psychological descriptions were effective in casting parental autonomy as excessive and pernicious, and encoding their resistance to counselling protocols as pathological and irrational. Professionals therefore had two kinds of discursive resources at their disposal: moral and psychological aspects of the child's autonomy would obstruct parental requests, while parental autonomy was explicitly problematised by casting psychological and moral aspects of conduct as blameworthy and feckless.

Another version of autonomy that presented both practical and ethical dilemmas for professionals was the cognitive and psychological version of the *autonomous* child. Professionals had the difficult task of distinguishing, firstly, *who* was consenting to testing: the child or the parent?; and secondly, *when* does the child or the adolescent begin to display informed consent about complex risk? Professional judgments of whether minors can reflect upon 'future consequences', 'abstract thoughts' or 'deductive decisions' were formulated as highly subjective and situational. Eliciting autonomy described the interactional difficulties of having to locate or verify the child's cognitive authority. However, it was implied by one professional that informed consent might be treated as a means to an end if adults have already agreed that testing is appropriate (cf. Extract 5). Psychological descriptions of children as independent entities and persons were also instrumental in equalising the presumably unequal relationship between parents and children. This cognitive and developmental version of autonomy would serve to justify the professionals' role as advocate of the child (cf. Extract 6) as well as gatekeeper of prospective risk communication (cf. Extract 7).

As we have seen, the main rhetorical function of professional accounts is *justifications* of professional practice. Descriptions and explanations of characters and events are reconstructed in such ways that justify professional conduct and endorse the child's autonomy. However, an important finding that is quite different to the justificatory role of accounts is the formulation of professional ambivalence. This is not specifically a dilemma of the child's autonomy, but a dilemma of professional conduct and authority. Professionals displayed ambivalence when explaining difficult encounters with parents ('And I don't know because it is a bit of a struggle') and children ('And when you've got a child in front of you, you know, that's- that's more difficult again'). Another related finding is that professionals seem to be defensive about their authority ('and that might be patronising and that may be paternalistic, but I think we do still have the child's interests at the core') and seem to anticipate potential criticism and complaints ('I'm not saying parents aren't the best people to make decisions for children'). We believe that both ambivalence and defences are related to the practical, interactional difficulties of blocking and deflecting parental requests without at the same time explicitly directing clinical encounters. The non-directive ethos of genetic counselling, for instance, does not usually or explicitly refuse genetic services. Other, more subtle, tactics are used which, as we have seen, encourage parents to consider 'the principles of this thing', to 'think it through' and consider matters from the child's point of view. In Extract 4, for example, the father is heard resisting the counsellor's suggestion of 'let's go through the whole idea' suspecting that further discussions will delay and discourage testing. Ambivalence and defences are therefore symptomatic of the power relations that are manifest in difficult interactions with parents and children regarding access to genetic services.

### **Conclusion:**

How might we characterise this style of reason that governs in terms of autonomy? The molecular politics of childhood testing brings out a peculiarly pessimistic and authoritarian dimension from the medical fraternity: only competent minors or adults should have rights of access to their genetic risk information. Presumably, this is justified because the predictive nature of genetic risk is immutable and individualizing. At the level of ethical policy, the notion of autonomy forms part of a liberal technology that constitutes the child as the bearer of rights and cognitive responsibilities with which they are to choose in relation to their own well-being. At the rhetorical level, we have seen that professionals employ situated strategies and tactics that seek to act on the complex and highly occasioned interactions with parents and children. They recruit the child as a device for facilitating ethical perspective-taking.

They contrast the pathological and intrusive aspects of parental autonomy with the child's fragile autonomy. They employ methods and techniques which do not strictly limit and forbid, but maintain a climate of negotiation and shared decision-making.

In this pastoral technology of genetic governance, medical professionals practice both caution and discrimination with regard to whom they provide genetic services. At the limits of these marginal and extreme cases, both liberal and authoritarian mentalities and practices are combined to responsabilize recipients of genetic information. These illiberal aspects of the politics of autonomy in childhood testing are by no means incompatible with liberal mentalities of rule. Others have noted, for instance, that the focus on 'the governmental uses of liberty gives liberal political reason far too good a press' (Hindess, 2001: 94). What is often played down in accounts of governmentality, and what is otherwise a symptom of medical paternalism, is the place accorded to authoritarian rule which has always played an important part in the government of states (Dean, 2002). The emergence of mutual obligation in medical decision-making does not mark a departure from neo-liberalism, but illustrates how liberal political thought operates through a range of techniques that not only govern through freedom and choice, but also deflect the rights and freedoms of some so that others might be potentially shaped into self-sufficient agents.

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