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Why Non-Directiveness is Insufficient: Ethics of Genetic Decision Making and a Model of Agency

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Abstract There is no consensus about the ethical ideal of genetic counselling and decision making. This paper reviews and discusses some of the most prominent ethical arguments that have been brought forward against the non-directiveness principle (NDP), which has been the ethical gold standard for a long time. These arguments can be classed in four categories: (i) NDP can be against the best interests of the individuals concerned; (ii) NDP has ideological elements that do not adequately represent the counselling ethos; (iii) NDP was historically a defensive tool that protected the interests of geneticists against social criticism and against litigation; (iv) NDP falsely assumes individual responsibility and hides the shared responsibility of other social actors. The paper argues that a serious understanding of moral space, which people need in order to make 'their own' decisions, leads to a necessarily relational concept of agency. The positive counterpart of NDP is to allow a space for agency. Allowing agency implies offering the kind of support that the decision-making person really needs. To make a good decision about personal genetics implies being empowered to act as a contextually sensitive person who is aware of relationships and corresponding responsibilities.

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Abbreviations

NDP	Non-directiveness principle
PGD	Pre-implantation genetic diagnosis
PND	Prenatal diagnosis

Introduction

Personal genetic information becomes available to individuals, families, caregivers and interested third parties in diverse situations. Decision-making situations may be difficult to understand and handle; many contain elements that individuals may experience as existentially demanding and ethically challenging. This applies not just to reproductive decisions in PGD or PND in the context of beginning or continuing a pregnancy, but increasingly to other fields of life where predictive genetic information is offered or risk markers can be tested. Non-directive genetic counselling is supposed to be a communicative arena where the autonomy and the best interests of the clients against third-party interests or societal pressure are protected. Providing neutral information but no practical advice or moral judgment should allow

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patients to arrive at self-determined decisions in the best sense of that term.

But there are shortcomings. The principle of non-directiveness (NDP), which is commonly accepted as the ethical base in genetic counselling, only marks the negative limits of a certain understanding of the duties and responsibilities in counselling practice, saying what counsellors should *not* do, but leaving open what they *should* do in order to meet the best interests of their clients or patients under the particular circumstances. This paper reviews and discusses some of the most prominent ethical arguments that have been brought forward against the NDP in genetic counselling. I will investigate the motivation and reasoning behind those criticisms, hypothesizing that a more affirmative interpretation of the positive counterpart of the NDP—agency and the moral space that agency needs in order to prosper—might be a way forward. The model of agency that I will then outline draws on a hermeneutical approach to the moral self and to the tasks that are created by the offer of personal genetic information.

Definitions and Fields

Genetic testing, screening and counselling are not only spaces where new freedoms are created. They can also be places where new obligations and restrictions emerge. *Genetic counselling* needs to be defined in its function, which emerged in a socio-historical context, as an empowering tool for the potential user of genetic information, which enables her or him to make the best decisions and to reliably interpret data from genetic tests. However, genetic counselling can also be seen more critically from a politically sensitive perspective, as a stabilizing element within an ethically ambivalent regime of "liberal eugenics" (Habermas 2003), where prevention includes the selection for life of only those embryos and foetuses carrying 'healthy genes'. The ostentatious avoidance of directiveness, which is coined as NDP, even assures moral legitimacy and averts the suspicion that genetics is a coercive measure.

In any case, genetic counselling in professional medical settings is one example of genetic communication, and it is certainly the one most widely investigated and morally reflected upon. There is a vast literature here that has no counterpart in 'lay' genetic dialogues.[1] I will take advantage of the high quality of the available literature and the well developed professional deontology of genetic counselling, reading it with a critical eye, to uncover lessons that also apply to non-professional genetic dialogues. My aim is to identify key elements in an ethical model of communication of personal genetic information. Obviously, NDP does not really work outside the field of professional counselling, because family relationships do not end after a 'session', and require much higher levels of mutual engagement and sharing of responsibility. This responsibility always has both an epistemological and a moral side. Medical, biological and genetic knowledge has to be transformed, interpreted and appropriated ("embodied", as Lippman 1999 has aptly described it), in order to make sense in a particular situation. The moral side comprises the practical dilemmas that may arise: Who should know? How I am going to tell, what and when? Which preventive measures should be taken? Or, in the case of PND, should a test be taken that might lead to a decision about abortion?

By the term *personal genetic information* I understand information that (i) is directly or indirectly produced through genetic diagnostics, genetic tests, sequencing or microarrays (gene-chips) that measure gene activity patterns etc., and (ii) has an impact on an individual. The word 'genetic' has a *pragmatic* component referring to the use of laboratory tools created by molecular and cell biology. But it has also a distinct *meaning*: it provides (or promises to provide) knowledge about the past and future developmental potential of our bodies. It seems to be knowledge about factors that are beyond our control, making us what we are by nature.

What is *non-directiveness*? For several decades, the criterion of 'non-directiveness' has been considered as the gold standard for respecting the autonomy of clients in genetic counselling. NDP is the guiding norm that governs the rules of social and medical availability of personal genetic knowledge. Genetic knowledge, however, is not just knowledge about an individual. It is also essentially *social*, because it is very frequently knowledge about more than one person. It is social in three directions: *backwards*

[1] I use the terms 'genetic dialogue' and 'genetic communication' interchangeably.

because it reveals knowledge about our ancestors, *forwards* because it anticipates the features of our descendants, and *lateral* because it has implications for other members of the family. In addition, genetic knowledge is not raw data, but is *interpreted* within a social context of symbols, texts, narratives and discourses about genes, embodiment and identities (Rehmann-Sutter 2002), and as information with a meaning; genetic knowledge is always therefore *mediated*.

In an introductory book to genetic counselling for professionals written about ten years ago, Ann Platt Walker introduced non-directiveness as a crucial component of the "philosophy and ethos of genetics services and counselling". She noted that adherence to a "nonprescriptive" approach "is perhaps the most defining feature of genetic counselling" (1998b, p. 8). Of course, in ethical evaluations of genetic services other related concepts play a role as well, like voluntariness or the right-not-to-know. Weil (2003), in a more recent critical assessment of non-directiveness, begins by emphasizing the central role of this principle: "For thirty years non-directiveness has been the guiding principle or central ethos of genetic counselling" (p. 199). According to these and many other statements in the literature, non-directiveness has been the key element of normative self-description in genetic counselling practice: its defining feature, the guiding principle, a central ethos. They leave open whether non-directiveness is actually practiced in reality. But first we need to know more precisely what the *principle* of non-directiveness is supposed to be.

Walker (1998a, p. 8) gives the following definition:

> Although the counsellor can use clinical judgment in choosing what information is most likely to be important and helpful in a client's adjustment to a diagnosis or decision making, it should be presented fairly and evenhandedly – not with the purpose of encouraging a particular course of action.

An early outline was given in a workshop of the (US) National Genetics Foundation and reported by Fraser (1974). Genetic counselling is "a communication process" that helps the individual or family to comprehend and appreciate the medical and genetic facts, to understand the practical options for dealing with the risk and to choose the course of action "which seems appropriate to them". The model situation of genetic testing was PND, and the course of action (which should not be directed by the counsellor) meant the termination or continuation of the pregnancy. In the current discussions of non-directiveness, we often hear simpler descriptions such as: genetic counselling "should not be prescriptive either with regard to testing or non-testing or with regard to the response to a given test result" (Holm 2005, p. 207).

Theoretically, non-directiveness could be defined by two clear cut rules:

(i) providing complete unbiased information
(ii) refraining from giving practical advice

But it is clear that this cannot be realized in a strict way, and in practice necessarily involves compromises. One difficulty arises from the variety of situations in genetic counselling practice that arise *beyond* prenatal testing. The course of action in response to a given test result obviously depends on the situation in which a genetic test is performed. If it is a diagnostic test, the response can be the application of one therapeutic treatment and not another; if it is a pre-symptomatic genetic test, the response can be a preventive measure; if it is a prenatal test, the response can be termination of the pregnancy; if it is PGD, the response can be the non-implantation of the embryo into the uterus after in vitro fertilization. The degree of openness required regarding the decision about the response varies, being presumably minimal in the case of a diagnostic test (where the course of action is essentially therapeutic and integrated into general medical treatment) and maximal in the case of PND (where the course of action may involve abortion). In PGD, the conditions under which the embryo should be implanted may be more or less decided before the test is actually done. There, the autonomy of the patient has its proper place at the point of decision making about IVF and in the planning of PGD but, due to lack of time, is less apparent in the interpretation of the results after embryo biopsy. And in pre-symptomatic testing or cancer risk counselling (at least in cases where high probabilities are detected), the medical advice will also be based on a therapeutic ethos if it is clear how to avoid risk factors and which preventive measures are appropriate.

One obvious conceptual difficulty appears in Walker's quoted statement: the counsellor should

not intend to encourage a particular course of action by the counsellee, but on the other hand she or he cannot avoid using clinical judgment in choosing *which information* is most likely to be important and helpful. Obviously however, much of the client's adjustment to a diagnosis and much of the client's decision making will in fact depend on which information the counsellor finds useful or necessary.

The reason *why* non-directiveness has gained such central importance in medical genetics can be explained historically. Medical genetics, as it was widely established first in the context of PND in the late 1960s (after the first successful demonstration of the normal foetal karyotype from cultured amniotic fluid cells in 1965 and the first abnormal karyotypes in 1968 (see Milunsky 1978), had a strong anti-eugenics program. Eugenics was a central element in Nazi ideology, and there was a widespread wish to reject it after World War II. Non-directiveness was a justificatory tool (Walker 1998a, p. 8; Wertz and Fletcher 2004, p. 36). Individualism was a crucial factor for the establishment of a stable network of actors in medical genetics, because it fended off any analogy with eugenics ("the unthinkable, the impossible, the 'this must never happen again'", Wieser and Karner 2006, p. 36) and could provide the basis for a morally acceptable framework: nobody is forced to anything, everybody can decide for him or herself. As Wieser and Karner point out, there were other supporting factors as well: to protect themselves against legal liability, doctors have an interest in informing the patient and not deciding for them (Wied et al. 2009).

Flaws in the Non-Directiveness Approach

A Sociological View

If NDP began as a solution formed within a given historical context, it has created new ethical problems in the present. In their study of the development of medical genetics in Austria, Wieser and Karner found that, in the field of PND, the non-directiveness regime radicalized the situation of pregnant women. "Being able to decide for oneself also means being obliged to do so and consequently being obliged to take full responsibility for the decision" (Wieser and Karner 2006, p. 36). The individualist appeal in NDP created a false picture, because the responsibility for the practice of prenatal selection is actually dispersed between many actors. In their normal prenatal care, the women slide into a pre-fabricated socio-technical system. It is a regime from which it is very difficult to escape. For the woman concerned, a moral *aporia* is created: she is obliged to be autonomous in a decision which calls her identity as a caring mother into question. Wieser and Karner call this a "conflicting individualization process", when genetic examinations let the woman ask: "Who am I as a mother if I am calling my unborn child's life in question?" (ibid.) An abortion is not just a decision; it puts many women under serious psychological and moral pressure. From the point of view of the woman, the individualist assumption that she alone should carry the full responsibility for this decision can be worrying, even cynical, given the real societal background.

Choice promises freedom, but it is at the same time inescapable. In current prenatal care practice, where women are given risk assessments from nuchal translucency in ultrasound (Schwennesen 2009), *not* to decide is no longer an option. The woman is already caught in a regime that governs by posing *inescapable* ethical questions (Wieser and Karner 2006, p. 36). If there is no counselling prior to screening, no free decision taking all potential consequences into account, then talk of "decision autonomy" has become contradictory. But even with pre-screening counselling, it is difficult to gather all the consequences and give them their proper weight. The decision about screening looks very harmless, just a first step in a course of micro-decisions, leaving everything open. It is a decision that is easy to take, because it is just about getting a better picture of the risks and chances; no invasive procedure and no risk of miscarriage are involved.

We can claim that this development in the practice of prenatal genetic counselling has actually led to serious tensions in the paradigm of decision autonomy. If the first innocuous step is taken, it is 'already too late'. The whole decision has become too complicated to grasp, therefore patients disentangle the whole into parts and bits, taking an overwhelming decision in a piecemeal fashion (Scully et al. 2007). While this is sometimes favourably interpreted as a means of safeguarding moral agency, it can also be seen as radically questioning the individualized

approach to genetic responsibility, at least in a framework where a decision is systematically offered in little spoonfuls, each relatively sweet to swallow.

A Counsellor's View

There is currently increasing awareness among medical geneticists and genetic counsellors that non-directiveness should be either replaced by another guiding principle or integrated into a more differentiated and broader ethos. As Walker (1998a) points out in the same paragraph from which I have already quoted, NDP does not always meet the needs of the patients: "… particularly in the presence of complex genetic and medical issues, conflicting data, or choices that raise problematic moral issues. Being entirely non-directive under such circumstances leaves clients to flounder." (p. 8) This is a serious point. Walker demonstrates a conceptual contradiction: to ward off eugenics, NDP should protect the individual against the collective. But if the needs of the individual do *not* demand the counsellor to be "entirely non-directive", the principle of non-directiveness cannot do precisely what it is supposed to do, i.e. protect the needs of the individual.

Clinicians' Views

In a paper written by six leading American geneticists and summarizing the results of a workshop at the 2003 Annual Education Conference of the National Society of Genetic Counselors, Weil et al. (2006) bring together a whole list of criticisms of NDP. The main concern is that NDP inhibits the development of effective counselling approaches, limits the use of the full range of counselling capabilities, and in effect does not promote the autonomy of the counsellee. It is itself a value-laden approach, because it shifts the attention from important issues to the process of decision making itself. It also provides an insufficient basis for a profession that addresses issues such as abortion and quality of life. Moreover, it fails to address the social and economic context within which individual decision making takes place. It is inadequate when applied to new areas of genetic counselling beyond reproductive decision making, such as cancer risk counselling. It also inhibits the development of creative approaches to the new challenges of genomic medicine and managed health care. Weil et al. impressively demonstrate the shortcomings of rationalist individualism and of its correlated ideal of non-directive counselling. An ethics that derives its analysis from the hypothesis of a rational and autonomous person is cut off from the interrelatedness that is essential to and inherent in genetic information. The reality of counselling is thicker, deeper, more ambivalent and morally more demanding.

The simplifications that are contained in the idea of the patient as a rational decision maker tend to alienate the ethical discourse from the local worlds of those involved, be they counsellors, researchers, patients or other family members.

When we look back at these different concerns and categorize them, four areas seem predominant:

(i) NDP can be against the best interests of the individuals concerned and does not adequately represent the needs of those who receive personal genetic information. We are talking here about those needs which are directed to the providers of personal genetic information. In professional counselling settings, the providers are the genetic counsellors and the concern addresses itself to their professional capabilities and strengths. The key ethical argument here is that those who can provide personal genetic information have a particular kind of power in their hands, and that those who receive it and may be personally concerned, because the genetic information is 'about them', become dependent and also vulnerable in a particular way. The relationship is asymmetrical. If the real needs of those receiving the information are not adequately taken into account, the ethical model is inadequate.

(ii) NDP has ideological elements which, in some situations, contradict the ethos of the counselling practice. These concerns are raised from the provider/counsellor perspective. Those who can provide others with personal genetic information may have a richer understanding of what they should ethically be expected to do than 'just' providing the information in its 'naked' form and keeping themselves out of the client's evaluation and decision making. The ethical argument which expresses itself in this group of concerns can be explained as follows. Providers

of genetic information that concerns others can have a fuller sense of responsibility as 'good and responsible providers' than information that can reasonably be captured with the NDP. NDP reduces the excellent fulfilment of their role, or their professional virtue.[2] It would be ethically problematic from the providers' perspective to follow a norm that is recognized as too narrow.

(iii) NDP had a historical significance as a defensive tool in the establishment of medical genetics. It works like a myth that stabilizes the network of actors in genetic testing, screening and counselling, especially in the realm of prenatal testing, upholding the idea that the medical offer of prenatal testing is morally defensible and innocent of eugenics. The ethical argument that is behind this concern can be put this way: instead of protecting the interests of the individual, it protected historically the interests of the geneticists against social criticism—and also against litigation.

(iv) Another group of concerns focuses on the false assumption of individual responsibility, or naivety with regard to the shared responsibility that is implied in NDP. It holds an individual responsible, assumes and ascribes this responsibility and places it as a burden on the one person who is expected to decide (about their own personal genetic information, about their own pregnancy etc.), where in fact the situation has been created by an extended network of actors who either will not be identified as responsible or will move into the background of the moral picture. The ethical argument is that responsibility is falsely ascribed to an individual who is in a vulnerable position.

Re-Modelling Genetic Dialogue

The concerns and critical arguments that have been brought forward against NDP also contain hints that can be put as positive requirements for an ethical model. (i) The best interests of the individuals and families concerned should be at the centre of an ethical model of genetic dialogue. This also means that we need a fair, reliable and realistic account of the needs of those who receive personal genetic information. More qualitative empirical studies are needed to get the necessary information about the recipients' situations and moral perception. Their moral perspectives count no less than the moral perspectives of the providers or the regulators. (ii) The counsellors are professionals engaging in a crucial existential communicative relationship with their clients. Their ambition is to do what they do as well as possible. In order to clarify what that means, the vast body of experiences from the professional practice of genetic counselling provide important case materials to investigate. (iii) Warding off moral reproaches (eugenicism) or financial risks (litigation) cannot be the aim and function of an ethical model of genetic dialogue. More important is to provide a space for all relevant concerns that may affect the decision, a space that is not tainted by ideologies. (iv) The discussion about an ethical model of genetic dialogue is an opportunity to clarify the actual network of responsibility shares that makes up the situation in which the individual is placed. This discussion has bio-political implications and therefore should not be excluded from the public sphere.

We see that in all this moral work in genetics, the NDP is not qualified as 'wrong', or 'bad'. Non-directiveness retains a kernel of moral truth, but as the basic norm or principle for genetic communication the NDP is insufficient and therefore needs to be integrated into a broader and more substantial ethical model.

Two strands in the recent literature about professional ethical ideals will now be examined: one showing to advantage the full implications of psychosocial counselling, the other triggered by the actor network approach.

(1) Weil (2003) made a new start and suggested that the NDP should be replaced by the methodology of psychosocial counselling: "The central ethos of genetic counselling should be to bring the psychosocial component into every aspect of the work" (p. 207). This takes up a development that goes back to early advocates of psychotherapy such as Rogers (1942). His 'person-centred

[2] The explication of the 'virtues' as human excellences is owed to Nussbaum (1990, p. 79), and Aristotle (2009), NE, 1106b 21–23.

counselling' is still one of the most influential theoretical approaches for addressing psychosocial issues.

It is puzzling to suggest that Rogerian psychosocial counselling should now replace non-directiveness, because the stance of non-directiveness belongs to Rogers' own central tenets (Marks 1993). It was the term that described his personal approach to psychotherapy, before he renamed his system "client-centred therapy" (Kessler 1997). But non-directiveness in the context of psychosocial counselling is a broader model than non-directiveness as it was applied in genetic counselling. This psychosocial model of non-directiveness describes the role and task of the genetic counsellor in terms of somebody who does much more than just provide the clients with relevant medical information and genetic facts, together with the options open to them. The psychosocial ethos is, as Biesecker (2003) explains, opposed to a purely medical model of counselling. And the practice of counselling is different from teaching. It is a different way of addressing and communicating information to people who may experience loss, hurt, frustrations, anger, indecision, and disappointment. "Yet it is both the cognitive and the affective meaning of genetic information and their lived experiences that are most relevant to genetic counselling clients" (p. 215).

The workshop report on non-directiveness presented by Weil et al. (2006) contains a series of interesting observations made by genetic counsellors that can be read like a focus group analysis. First, it was clearly stated by participants that non-directiveness has its proper place within a more general goal of promoting the autonomy of patients. Genetic counsellors should "help" patients in the best possible way. Weil summarizes the discussion by saying that speakers at the workshop supported the idea of "more proactive counselling from a variety of perspectives: giving more attention to the wants and needs of counselees, creating a comfortable setting within which counsellees can use as many of their faculties as possible, facilitating active decision making, implementing meaningful informed consent, and identifying and processing genetic counsellors' personal and professional values" (p. 90). In his commentary Weil clarifies the role of non-directiveness: "It may serve as a component of the ethical basis for clinical practice, *insofar* as it supports attention to and respect for client beliefs, values, and personal circumstances, promotes client autonomy within an appropriate cultural framework, and supports effective, knowledgeable decision making. However, it is not a theory of clinical practice, and thus it cannot serve as a primary theoretical underpinning for the profession" (p. 91, my emphasis). A parallel argument is made by Scully (2009) who questions whether the rule of abstaining from giving any direction in the counselling encounter serves patient autonomy. Promotion of autonomy is the underlying ethical rationale, and non-directiveness is important insofar as it serves it. If we take this line of argument seriously the NDP is not wrong, but it is too limited in scope to capture the ethical aims of genetic counselling practice.

A second point in Weil's commentary on the workshop report is relevant, because it explains how autonomy can be understood in this context. The counsellee is involved in a "psycho-education process that involves two-way interactions between the genetic counsellor and each counsellee, as well as more complex interactions involving three, four, etc., individuals, both present and absent from the counselling session" (p. 91). In this interaction that extends beyond the counselling dyad, medical facts and psychosocial aspects are woven together in order "to help patients understand their situation and make good health decisions for themselves and their families" (ibid.). I note that autonomy is here rather a *relational* capacity of the self: the patient wants to make good health care decisions for her- or himself and the family. And this capacity is to be supported in a two-way communicative setting together with a counsellor, who helps to weave together medical facts, emotional meanings and the implications for others outside the consulting office.

A further important step was the publication of the report from a consensus conference of directors of genetic counselling graduate programs in the US by Patricia McCarthy Veach, Dianne M. Bartels and Bonnie S. LeRoy (2007). They started by formally defining the structure of a 'model of practice', which in their terminology is different from a 'definition' of that practice or from the 'scope' of that practice. The model of practice "constitutes a systematic method of problem solving that is applied to clinical situations and is based on scientific process. A model provides:

(1) a tentative theoretical framework for organizing interrelated theory, research and practice; (2) a common frame of reference for the systematic assessment of patients and the development of interventions; (3) a common frame for all practitioners in the clinical setting […]; and (4) consistency and continuity of care in the delivery of clinical services" (p. 714). This approach can meet many of the shortcomings of the 'central ethos' approach, which were pointed out by Biesecker (2003). The central ethos is embodied in a model of practice. It is not principle-based but is much broader, closer to real experiences, and contains many levels that can be implemented practically, and monitored. In the presentation of key elements for a model of practice Veach et al. draw on Rieh and Ray (1974), who describe a model of practice as containing *tenets* (principles, doctrines, or beliefs held in common by members of a group), *goals*, *strategies* and *behaviours*. The consensus conference resulted in the formulation of five tenets and their corresponding goals, strategies and behaviours. Here I list the tenets and goals:

> Tenet 1: Genetic information is key. *Goals:* Counsellor knows what information to impart; counsellor presents genetic information; patient is informed; patient gains new perspectives.
> Tenet 2: Relationship is integral to genetic counselling. *Goals:* Genetic counsellor and patient establish a bond; good genetic counsellor-patient communication; counsellor characteristics positively influence process.
> Tenet 3: Patient autonomy must be supported. *Goals:* Establish working contract; integrate familial and cultural context into counselling relationship and decisions; patient feels empowered and more in control; collaborative decisions facilitated.
> Tenet 4: Patients are resilient. *Goals:* Recognize patient strengths; adaptation; empowerment.
> Tenet 5: Patient emotions make a difference. *Goals:* Counsellor and patient know patient concerns; patient's family dynamics are understood by counsellor and patient; patient self-esteem is maintained/increased (Veach et al. 2007).

The tenet that genetic information is key expresses the assumption that being informed is in general better than being uninformed. Patients who attend genetic counselling desire genetic information and want to have it explained in a way they can understand. They want to understand genetic information in order to be able to draw their own conclusions from it. The second tenet says that the relationship between counsellor and patient is key. Genetic counselling is therefore seen as "a relationally based helping activity whose outcomes are only as good as the connection established between the counsellor and patient" (p. 721). The tenet concerning autonomy suggests that the patient knows best and therefore should be self-directed regarding practical decisions. The individual and her or his socio-cultural and familial context are valued and respected. Perhaps surprising is the inclusion of a tenet that patients are resilient. The explanation is that counsellors assume that the typical patient (not each individual patient) is hardy enough to participate as an equal in the genetic counselling process. She or he can adapt to difficult and painful situations. Given appropriate information and adequate psychological support, patients can draw on their capacity to learn. Assisting clients involves recognizing their strengths in the face of genetic information. The word 'empowerment' is used several times to express what is at stake.[3]

(2) A second strand of discussion that is relevant for understanding the impacts of genetic communication comes from the sociological and anthropological camps. A common theme is the social construction of the individual decision-making situation. One can analyze the biomedical construct that creates a desire, even a responsibility, to consider genetic testing and counselling, and to engage in decision making as a system of 'distributed action'. It is not just 'the test and me', or 'the counsellor and me'. There is a much larger socio-technical system behind it that produces the apparent dyad. The process of individualization of responsibility, for example for PND, is not morally neutral because it places the burden of a system of pre-organized decisions on the shoulders of essentially one person—the pregnant woman.

[3] The empowerment perspective has been introduced to the autonomy discussion from a psychological perspective by McConkie-Rosell et al. (1999).

'Actor Network Theory' is a theoretical approach that provides a framework for analyzing socialized action in socio-technical systems. Actions, according to Latour (1999), can be distributed over many 'actants'. Actants can be persons, institutions or even objects, predominantly human-made (like ultrasound scanners, laboratory tools, DNA test kits, or sequencers). This framework allows us to analyze practices as 'actions' performed by hybrid conglomerations of different persons and things, all necessary and co-responsible for the shape and meaning of the action: "human-technology conjunctions" (Wieser et al. 2006, p. 124). They realize the action as a collective achievement. And it is clear that behind the technical things involved in such conjunctions stand other human actors who, intentionally or unintentionally, have constructed, produced or purveyed these things that are now used for this purpose, and that shape the plans of the users.

For prenatal testing this approach has an obvious application. Consider the risk assessment examinations before invasive testing that are carried out in PND. Non-invasive screening methods produce increasingly reliable indicators for the realization of invasive examinations. This means that examination begins at an earlier stage of pregnancy. Non-invasive screening methods are applied to more patients, and to younger women. Ultrasound devices are available in most gynaecological practices. The risk is no longer shared in a group (for instance an age group) but appears as an individualized risk estimation (a number belonging to the individual). The overall decision is therefore sequenced and split into a series of sub-decisions. One examination can lead to the next, one result calls for the next examination. However, the decision about screening (in contrast to testing) is not normally perceived by the women for what it is. Or it appears so provisional that it is easy to take: the only outcome is that the next decision can be taken with better information; and it is not invasive. Counselling is offered before and after invasive tests, but rarely prior to non-invasive tests. All these elements together (I have taken them from Wieser et al. 2006, pp. 106–108) shape the 'action' of PND. The woman plays one part in a larger choreography that she has not written herself. Her part, however, essentially implies the adoption of the key responsibility for the whole distributed action, performing an individualistic account of autonomy.

The role of ethics here must be to create spaces, if necessary counter-spaces. Ethics, after realizing the distributed character of responsibility and the *function* of individualist interpretations of autonomy, can no longer naively play along the pre-set rules, reinforcing and legitimizing the system by providing the moral background theory for individual decision making. Ethics should rather publicly draw attention to the real patterns of responsibility. They can be revealed when looking beyond the assignment of responsibility to the individual. Recognizing the distributed nature of responsibility in the essentially social practice of PND must therefore have consequences for the understanding of ethical issues in PND. "If action is distributed this can only mean that responsibility is also distributed" (Wieser et al. 2006, p. 125). In other words, the individualization of action is a kind of false consciousness, functioning to stabilize the actor network as it is, i.e. the Foucauldian 'biopower' is working through the network. Individualizing forces must be one type of factor to be recognized by the individual involved, in order to become capable of coping with the demands of the situation.

In another essay, Wieser draws out consequences for the ethics of counselling and calls for a deepened understanding of empowerment in counselling. The woman is coping with a regime, a form of informal governance. In order to gain moral agency in this situation, she must become capable of *understanding* what happens, where her options are, how she can participate in *reshaping power*. This is an important aspect of empowerment, and should be further developed in future ethical studies on genetic counselling. Charting responsibilities in a complex network of actors, and decoding the hidden programmes in technological arrangements is a crucial step. The individual can then participate more actively.

As Margaret Urban Walker pointed out, vulnerability in such networks is socially constructed, and moral philosophy has the task of deconstructing and reconstructing the social patterns of responsibility, in order to create spaces of agency (Walker 1998b, p. 94). This may also affect the role of ethics, as Wieser (2005) mentions: ethics is not just a communication or a branch of philosophy dealing with rational arguments and norms, but it is also *a place and organization of a process* that allows—more or less efficiently—for clarification and the empowerment of those involved.

Beyond the Counselling Office

Approaching an ethics of genetic communication, we need to be aware that when we speak of 'counselling' we always assume the presence of a professional and a client who desires to be informed and supported in some way. However, the professional setting is not the only social context in which communication of personal genetic information occurs and where ethical questions about disclosure or non-disclosure arise.

Examples are easy to find. In order to know which mutation could be present in a patient, the geneticist frequently needs to know the mutation of another person in the family who is affected by the disease. The patient will frequently be the one to ask this person for a blood sample or for test results (Gaff et al. 2007). Even in the professional counselling encounter the patient (or client) works creatively with the knowledge received. There are various transformative, interpretive, and integrative processes, in which counsellees are engaged in refashioning received biomedical information, "taking ownership of it and weaving it together with their own experiences and understandings and with 'inside' information, their feelings and beliefs" (Lippman 1999, p. 259). Such processes of appropriation and transformation of knowledge into 'embodied knowledge' integrate the dialogue in the counselling room into a vast outside space of lived experiences, relationships and life histories, rather than the other way round. And more recently, there is a growing phenomenon of genetic testing without any serious counselling at all: where genetic tests are marketed directly to customers (Human Genetics Commission 2007). In such instances, questions arise about disclosure and non-disclosure, about understanding the bits of knowledge, and about identifying the appropriate practical consequences.

Let us look at a case. Svendsen (2006) has studied Danish cancer risk counselling and the experience of one pair of sisters, Pia and Rosa:

> Both in their 30s, they sought advice because they were concerned about breast cancer in their family. Pia was healthy but her mother and aunt had both been ill with breast cancer and her sister Rosa had recently been diagnosed with breast cancer. Other relatives had also suffered from cancer. In the counselling session, before genetic testing, based only on their family tree, Rosa and Pia were told that it was probable that their statistical risk of having the mutated gene was 40 percent. "The counsellor listened to their story and told them that their aunt and nieces might also be at risk for hereditary cancer and that, if they were, then prophylaxis was also a possibility for them. She said that in order to make a more precise assessment of their and other family members' risks she would have to obtain their aunt's medical records, along with those of Rosa and her mother. It was up to Rosa and Pia to provide an informed consent form signed by their aunt so that the counsellor would be able to incorporate her medical record into the investigation. Rosa and Pia were a bit hesitant to contact their aunt. They discussed who should do it and, in the end, decided that they would ask their mother (who was not present) to do it." (Svendsen 2006, p. 145f.)

The mother, in this case, becomes an accomplice in a preventive regime; others become potential beneficiaries of preventive possibilities that come with genetic knowledge. Within their different roles they also take on commitments and responsibilities. The representation of increased risks, as charted upon a family tree, also indicates a moral commitment to a particular group of people and to particular forms of intervention. Acting responsibly means passing on information that may enable them to initiate preventive measures like further testing, more frequent check-ups, or even prophylactic operations. The aunt to be contacted, however, lived outside the circle of their mother's close family relations. Mother and aunt had "had very little contact over the last 10 years." And the aunt herself had three children aged between 27 and 34, the older two daughters being married with children. The commitment to contact the aunt, based on the moral imperative of disease prevention (Koch et al. 2005), leads to a communicative intervention with serious implications for those informed. The hesitation due to the estrangement within the family must (as they see it) be surmounted in order to pass on the information about further preventive measures, together with the knowledge about the probable existence of a familial genetic risk.

Commenting on this situation, Svendsen speaks of a difference between the biological ties and the social ties: "a gap between Rosa and Pia's *mapped* and *experienced* kinship" (Svendsen 2006, p. 150, my emphases). And she points out that the experience of such a gap can constitute "a *space for agency* in which genetic knowledge of kinship and risks is interpreted and relatedness is created" (p. 157). The existence of such a gap will not undermine responsibility. Genetic ties can appear to prevail over the social. Communicative relationships will have to be initiated, sometimes developed from scratch, based on biological relatedness. Sometimes this is impossible (as in the case discussed in Ashcroft et al. 2005). With this move, the space for agency turns into a challenge with an ethical impact.

Bearers of genetic information do not see the commitment and responsibility that is placed on them as objective facts in their situation. They are not part of an agreed-on system of rules and obligations; there are no rules of professional conduct or good practice. It is rather the result of their personal interpretation of the meaning and of the potential consequences of telling or not telling for those concerned. Such interpretation seems to be fundamental and constitutive for *local* responsibilities and commitments.

Responsibility and Vulnerability

In Svendsen's case study, knowledge about probable genetic risk was sufficient to establish this responsibility and commitment. Various conceptions of responsibility could be considered to make sense here. A minimal conception assumes responsibility when an effect can be attributed to an agent. Then, the agent is answerable, accountable (Widmer 1996, p. 21). But this account would only give a negative understanding of responsibility, as excluding determinism of the action (Kapitan 1995). But responsibility also "supposes the capacity in the agent of being aware of the effect of his, or her, action, whether the action was intentional or not" (Widmer, ibid.). The agent, in order to be responsible, needs to have the capacity for awareness of the consequences of the action for the person concerned. This is not a simple anticipatory task, because many things beyond medical facts and health prospects may need to be considered. The action itself might be unintentional (disclosing the information by accident) or intentional. In both cases responsibility is there, but with different meanings. The unintentional disclosure would not establish responsibility for a communicative action in the sense that Niebuhr (1963), p. 57), in his analysis of responsibility, has called an "answer to actions upon us in accordance with our interpretation of such action".

Niebuhr's account is helpful here because it captures more of the sense that actors in real life connect with the questions of responsibility. Responsibility, as the word suggests, is essentially a *response*: an answer to actions upon us according to our interpretation of these actions and with the expectation of the response of others to our response. Answering presupposes hearing and understanding. To see (or hear) the relationships and actions that constitute the situation, to interpret them in order to understand, sometimes realizing tensions and ambivalences, identifying the vulnerabilities of others and of oneself, leads to local knowledge about the situation and how to act in it. People who disclose genetic information to family members feel the dilemma between the desire to protect relatives from potential harm arising from the information, and the wish to provide them with helpful information that may have important health consequences (see the meta-analysis of 29 qualitative studies by Gaff et al. 2007). In weighing conflicting responsibilities, the individual assesses the vulnerability of the recipients of the information as well as their receptivity (Hamilton et al. 2005).

Acknowledging the needs of the other (to be informed and to be protected regarding their vulnerability) implies the establishment of a relationship of responsibility. The other is a person to whom one's own action is an answer. This person *counts* for the assessment of the consequences of the power one has (in the sense of the "power-over", see Ricoeur 1992, p. 220), which could be misused in violence. This power-over-the-other is not primarily a power over the other's will, but rather a power over the other's well-being and luck. This, I believe, is the connection between vulnerability and responsibility, which can be realized in disclosing personal genetic information.

How can we understand vulnerability in this context? It is not vulnerability in general (to someone or other) but concrete, direct *dependency-in-fact*, i.e. in Svendsen's case, vulnerability to Rosa and Pia's

actions in particular.[4] Vulnerability therefore involves a relationship of dependency (arising from the circumstances) upon somebody to secure or protect some important need or interest. The dependency emerges here because of the nature of their *biological* relationship (represented by the family tree), not because of some prior agreement or an existing close personal relationship between them. This can add to the moral difficulty that is experienced by the informant. The social relationship may not preexist or it may not be prepared to carry *that* load, and therefore may not provide a secure platform for dealing with the additional issue represented by genetic information. If the relationship does not preexist, is weak, or has a different character than would be needed, there is a morally experienced demand to *develop* the relationship in the course of communication about the genetic issue.

The fact of dependence is obvious, but its content is not. Dependence may be a complicated relationship, as can be seen again in the case of Rosa and Pia. The cousins, who probably do not know about the genetic risk in their family, are dependent on Rosa and Pia to obtain the information. This is their vulnerability to non-disclosure. But they are also dependent on Rosa and Pia in many other ways, for instance that they do not cause damage through insensitive communication or do not breach confidentiality towards third parties. This is their vulnerability to disclosure. Vulnerability hence arises with regard to disclosure *and* to non-disclosure.

Metaphors that Explain Genetic Information

Let us now take a closer look at the knowledge involved. Genetic knowledge is not self-explaining to clients, not even to doctors. It needs to be interpreted. And how it is interpreted, which images and metaphors are used to interpret, plays a role for what "information" is produced of the data and provided to the client. Genetic knowledge is not just what is written in the report that comes from the genetics lab. It is not just the correct description of a regular or special sequence of DNA and its accidental mutation at a particular location within the genome. This is raw data. In the context of medical genetics, counselling and dialogue data must be transformed into something that makes sense for human life. It is necessary to speak of information as something that is *meaningfully explained and understood* by those seeking information, and interpreted in various ways (and sometimes misinterpreted). The myriad of findings in molecular genetics need to be integrated into an understandable basic picture that says what it is all about. There is a set of powerful metaphors easily available in the cultural system that perform this role in genetic discourses. But they need to be scrutinized because they may contain problematic assumptions. Genomes, it is said, are "blueprints" for the organism; they contain a "code" for life, a "language" or a "list of instructions". Perhaps the most central metaphor for the role of the genome in the organism in twentieth century genetics was the "genetic program". It was generated and brought into circulation in the late 1950s by eminent biologists such as Jacques Monod, François Jacob and Ernst Mayr (Kay 2000). It contained the hope that by knowing and understanding the 'information content' of the genome, i.e. the sequence of DNA, we would be able to predict large portions of the structure and functioning of the whole organism. The idea of the genome as 'genetic program' ('instruction book', 'script' for development etc.) is still commonly used and provides powerful interpretative patterns, which are frequently used to 'explain' the significance of genes.

Within molecular biology, however, it has become clear that this imagery is misleading. There are real scientific problems with it, arising from the vast evidence for the *multi-functionality* of genes. One and the same gene can have different functions and play different roles in the context of metabolic processes, according to time, and the exact place of the cell within the developing multi-cellular organism. There are phenomena like alternative splicing, overlapping genes, alternative reading frames, trans-splicing,

[4] Here I use the phrase "dependency-in-fact" that has been introduced by Walker (1998b, p. 84), in her discussion of Robert Goodin's well-known principle of vulnerability. The notion of vulnerability is explained as follows: "X is vulnerable to Y in respect to N when X is *actually depending on* or *circumstantially upon* Y to secure or protect N *because* of the nature of their existing relationship, some prior agreement between them or by them, a particular causal history between them, or the fact of Y's unique proximity and capability in light of X's extreme plight" (ibid.).

anti-sense transcripts, mRNA editing, selective methylation, site-specific multiple function of genes and gene products, which are all at odds with the 'program' model of the genome (Fogle 2000, Griffiths and Stotz 2006). The basic picture of current genomics and systems biology is not the genome organizing the development of the organism with a series of prewritten instructions, but rather the developmental system, i.e. the cell or the organism (or the organism-within-environment), organizing the actualization of genetic information in the developmental process. Alternative metaphors of the genome–organism relationship are under discussion (Turney 2005, Neumann-Held et al. 2006, Rehmann-Sutter 2008), which are better suited to incorporating the evidence of multi-functionality of genes: a musical score, a library or a road network, rather than a coherent literary text. These are still anthropomorphic but point in another direction than the genetic program.

In a systems approach to DNA, mutations, personal variants of genes that are related to diseases, cannot be interpreted as 'information for the disease'. They can be correlated with an increased likelihood that a disease may occur and as such they are *indicators* for this increased likelihood (in some cases of monogenetic disease even near certainty). However, it would be a misinterpretation to say that mutations are a 'prescription for' or a 'gene for' the disease. In the body of the person concerned there is, for example, no information 'for cancer' if somebody is diagnosed with a mutation that increases the likelihood that a type of tumour may occur sometime in the future. In the framework of a systemic account of genomics, a cancer-related mutation is not a dangerous factor just waiting in the body or in some parts of the body *at present* to break out (like a time bomb). The frequently used terminology of 'predisposition' still implies the program genomics view that information is already present, pre-disposing the body. An expression that is more congenial to systems genomics is 'susceptibility'. Being susceptible, more or less susceptible than the average, does not imply the pre-existence of genetic 'information for…', but refers to variations in the probability that at some point in the future a constellation will arise whose combination of factors (DNA and other) leads to the development of the disease. I know that for monogenetic disorders this is more difficult to figure out than for polygenetic conditions like familial tumour diseases. But even there—Huntington's is a good example—in the time before the disease manifests, the person can know that she or he carries the gene that at some point in the future will probably contribute to the manifestation of Huntington's disease, with its characteristic symptoms. But at present, the person's body is not carrying the 'information for Huntington's disease', because we do not need to assume that this information exists yet. What can be seen via a test is the gene mutation that will become involved in the pathogenetic processes leading to the disease.

The talk of "genetic information" as "personal information" is flawed as far as genetic information is probabilistic.[5] What probabilities mean for the person cannot be explained without referring to metaphors. The selection of metaphors influences the meaning and significance of genetic data for the person. The difference between programmatic and systemic interpretations of genomics that I have outlined here, each as an ideal type, has a deep impact for those who introduce genetic test results into their worlds of self-understanding and embodiment. It makes a difference whether one sees a mutation that indicates a genetic risk for developing, for example, a cancer as *understood as* a section of the genetic program, i.e. as an instruction to the body to make cancerous tissue, or, in the framework of a systems approach, as a factor that could in future become involved in a process leading to cancerous tissue. Genetic hermeneutics matters.

Allowing Agency

When we are looking for an ethical model of genetic communication we need to consider all the points that we have elaborated so far. We then need to discuss a few assumptions, which seem common sense and easy to accept. A first assumption is that there is a fundamental ethical requirement of respect for (1) the autonomy, (2) rights and (3) health and welfare of those who need to take decisions about genetic information and about the practical matters that surround them. (4) I further assume that this holds

[5] I am grateful to one of the anonymous reviewers for suggesting this point.

true for all genetic communication, wherever it takes place, not just for the exchange of information between professional counsellors and their clients. (5) It has become obvious that the needs of those who receive or must handle genetic information in an appropriate way are broader than just being informed about the biological and medical implications of genetic testing and information. (6) We can furthermore assume that it is the needs of those who receive information and must adjust their behaviour, which make an ethical model of genetic communication ethically defensible. It should not be the dominant ideology of society or some universal account of 'normality' or 'human nature', or the interests of some third party. Therefore, patients in prenatal genetic counselling, for instance, need to be listened to, and invited into discussions, where scientific and other 'facts' can be looked at from different angles, rather than being educated (Lippman 1999). They need counsellors who believe what women say when they express their embodied knowledge, and accept its validity rather than considering it something to be corrected. Of course they also need to understand relevant medical and biological information about their foetus, or about the significance and the limits of the test. And they need to prepare their decision so that it will be their own and they can live with it in the future. The needs in other contexts can be different.

This said, I propose the following formal statement as a basis for further clarification:

> Good communication of genetic information enables a good decision or action to be found, all things considered.

The statement links two activities together, both qualified with the word 'good': a good communication and a good decision. By a *good decision* I understand essentially a decision that those responsible for or affected by can identify with and live with. This implies a requirement of respect for persons as moral subjects who can make decisions about their own lives. *Good communication* is related to good decisions as an enabling contribution. A communication is considered as good, if it enables the subject to make good decisions.

If we take the statement as an explication of good communication, it combines six ethically critical elements:

> Good communication is (1) a respectful interaction that (2) enables somebody to find (3) her or his own (4) good (5) decision or action, (6) all relevant things considered.

A few explanations for each element:

(1) Respectful interaction is driven by fully recognizing the other as a subject of a life. The other person in a respectful interaction is a centre of experiences that cannot all be anticipated. The other is not only a receiver of information, but a person who needs to be *heard* as an irreplaceable subject who can be vulnerable to different psychological and social implications and pressures of many kinds, and as a person who works through moral ambivalences, who has particular needs, goals, values, hopes and fears.

(2) To enable somebody to find a good decision or course of action means to provide relevant information, to assist in interpreting and understanding this information in a broader context of life, to make a difficult situation more transparent, to create a situation where a decision or a course of action can be developed without pressure, and to empower her or him by hearing them into speech (Morton 1985).

(3) A decision or course of action is a person's own if he or she can identify with it. This does not presume an individualistic account of autonomy but allows other, more inclusive or relational approaches, like being in harmony with oneself and with relevant others. The way of finding a decision or course of action that somebody can identify with may differ between persons and situations. Some may prefer a more self-centred approach, others a more other-centred approach; some may proceed more rationally, others more intuitively. Sometimes, telling 'what I would do if I were in your position' is the best starting point in a process that leads to an authentic practice of the other, but in other situations it may be an undue bias. What is important here is not so much that the decision or course of action is found in a way that accords with one of the established models of moral philosophy, but rather that it accords with the type of situation and the client's personal style of moral thinking and feeling. Lippman (1999) mentions that some of her interviewees told the decision story

about PND in retrospect as a story where an original 'feeling', however vague, was finally confirmed with arguments. Perhaps there were other 'feelings' around as well, but one indicated the right direction and helped the woman to identify with the outcome of the decision.

(4) 'Good' is a key word in the statement, indicating that the decision or procedure is more than just functional for reaching certain short-term goals (instrumentally good). A good decision or procedure is perceptive for all circumstances of the situation and in harmony with long-term life projects that are intrinsically worth being striven for. A good decision-making procedure is, to use a favourite expression of Nussbaum (1990, p. 148), "finely aware and richly responsible". Genetic dilemmas, however, are often situations where not just one long-term goal is relevant, but where different goals may conflict. Then they need to be evaluated and weighed against each other in such a way that the result of the decision-making process seems to be the best possible way forward within the given circumstances, limits and possibilities. Here, the values of the person who becomes the author of the decision are the reference, not the values of the counsellor or of the person who provides genetic information. But sometimes a person wishes to exchange views about values and to broaden his or her understanding of what is ultimately valuable. Genetic communication is often therefore essentially *about* the concrete understanding of what is relevant in a 'good life' or a 'fulfilled life'.

(5) A decision, action or procedure is a practical response to the situation. It does not necessarily mean the choice of action as one of several 'options', as they are often represented in the image of the 'decision tree'. The image of the decision tree is a metaphor that can help to clarify a situation, but is not necessarily sufficiently complex to represent what is actually at stake for the person. The decision tree, with its options as branching points, is a rather static representation of practice. People who make difficult 'decisions' may gain time and insight by proceeding in smaller steps, or micro-decisions (Scully et al. 2007), perhaps opening more options at each point or allowing the development of more clarity than is available at one given point in time.

(6) All relevant things should be considered. This often implies prioritization within an overly complex situation, and it also implies having the relevant information available. Genetics certainly contributes to the set of relevant aspects in those life situations we have been considering here. But relevance is an evaluative term. Not all that seems medically or scientifically relevant is also personally relevant, and vice versa. Genetic communication is a place where relevance *is negotiated* in processes of interpretation and understanding, bringing different perspectives together.

This is only a rough description of the primary elements of an ethical model for genetic communication, which is in several ways broader and richer than the NDP, without jeopardizing the respect-for-autonomy element and without falling back into a paternalistic attitude. We might also need a shorthand expression for the model that characterizes it as a distinct approach to the ethics of genetic communication and which is still substantive or explicit enough to be interpreted in specific circumstances. Parallel to the slogan of 'non-directiveness', which can be read as a one-word expression of an ideal, I suggest we can say that our model of communicating genetic knowledge is ethically oriented to *allow agency*.[6] This is its key aim.

Agency is a term that, if carefully examined, covers all six elements of the model. The person needs to be heard and recognized as an agent, i.e. as a subject of evaluation, responsibility and moral practice. Agency means that one has room to be responsible and to respond, the space to cope with pressures of any kinds, and that one is free and able to act. The understanding of what is relevant in the situation, of what should be seriously considered, is a resource for performing this capability. Agency also implies that the agent is sovereign in the sense that she or he can find her or his own practical response. Somebody is allowed agency if he or she can evaluate the course of action with regard to values and long-

[6] Lippman (1999, p. 272) has used this formulation with regard to religious or cultural reasons that can in some instances counter the weight of professional advice and "allow women agency".

term life projects, such as understandings of a 'good and fulfilled life'.

Agency is a term from social philosophy that recognizes individuals as social agents who are able to act responsibly (Barnes 2000). Paul Ricoeur, in his last book, which explains an ethical theory of recognition, uses the term 'agency' to cover the essentials of the morally capable human being that are not (or not fully) covered by the person's well-being: "We can see the person, in terms of agency, recognizing and respecting his or her ability to form goals, commitments, values, etc." (Ricoeur 2005, p. 142). A concept of agency for genetic communication can be further elaborated along these lines.

Allowing agency preserves the best parts of the NDP: respect for the client's values and responsible information. But it has no individualistic structure and does not prescribe a detached attitude for those providing genetic information. They are partners in a mutually engaged and caring interaction between persons with different roles, with asymmetric knowledge resources and an asymmetric distribution of decision loads.

Conclusion

The ethics of genetic communication in the post-non-directiveness era is no longer a separate field of professional deontology, but appears as a place where the deepest forms of ethics are performed on a practical level by those involved. It may not surprise that the role, duties and responsibilities, which are demanded of a counsellor, are very similar to the role, duties and responsibilities of a clinical ethicist, who sees her or his duty not in prescribing what is good but in enabling a good decision to be found by the actors. 'The gene' is in a certain sense de-professionalized and again re-professionalized to become an essentially pluri-perspectival entity with a variety of meanings and practical readings, whose trajectories depend on the circumstances and contexts. Local knowledge matters, local experts emerge. Professionals must find their roles and their excellences in relation to them. In mutually responsive communicative interactions they are partners in negotiating and re-negotiating what others see as good and relevant.

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