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See other entries Genetic Counseling; see also Reproduction, Ethics entries; Reproduction, Law, Regulation of Reproductive Technologies.

REPRODUCTION, ETHICS, THE ETHICS OF REPRODUCTIVE GENETIC COUNSELING: NONDIRECTIVENESS

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OUTLINE

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INTRODUCTION

In reproductive genetic counseling, nondirectiveness may refer to an ethic of practice or to the process itself. Different aspects of genetic counseling have been described as nondirective: the communication style, the offering of genetic testing, or the counseling interaction. These various interpretations of the term nondirectiveness have lead to confusion about the goals and practice of reproductive genetic counseling. As well, it has diluted conversation about important issues surrounding the personal nature of reproductive choice involving genetic risk. As an ethical principle, nondirectiveness suggests that pregnant women and their partners ought to be supported to make autonomous decisions about prenatal testing and their reproductive outcomes without the direct influence of the counselor. The personal autonomy of the client facing the genetic reproductive decision is paramount. Nondirectiveness should be used exclusively to describe an ethical principle in reproductive genetic counseling. Although it is not evident always how this principle translates into the practice of genetic counseling, the process may be discussed as a dialogue of client-centered counseling that is guided by nondirectiveness.

NONDIRECTIVENESS IN GENETIC COUNSELING

Nondirectiveness describes components of a young medically related professional service, called genetic counseling. This psychoeducational practice assists people who have concerns about birth defects, genetic conditions, or genetic risk (1–3). Throughout its short history, genetic counseling has been consistently described as nondirective, as opposed to advice giving. Genetic counseling may be the only medically related practice intended to be nondirective. The term has been used to describe not only the ethic of practice but also the goal of genetic counseling, the process, and an outcome. The literature discusses nondirectiveness assuming one of these practice components but frequently fails to distinguish its meaning. For those who strive to understand, to investigate, or to use genetic counseling services, it is unfortunate that the concept is inconsistently portrayed. Even those who practice genetic counseling have confused the meaning and interpretations (4,5).

Several scholarly articles have appeared to address the confusion in the meaning of nondirectiveness (4,6,7). The literature has begun to distinguish the various uses of the term in an effort to achieve some consensus on the goals and process of genetic counseling. Since the literature on nondirectiveness is discrepant, this chapter will delineate uses of the term and compare their implications. The success of the practice of genetic counseling depends on continued efforts to define and strive towards nondirectiveness assuming the profession can agree on what it is, that it is central to the process and that it can be achieved.

HISTORY OF NONDIRECTIVENESS

The original introduction of nondirectiveness into the genetic counseling literature remains elusive. Sheldon Reed, a medical geneticist who coined the phrase “genetic counseling” in 1947, spoke of a nondirective-like practice but only used the term later in his writings after it had appeared in the literature (8). Reed described a genetic social worklike practice of explaining genetic concepts and supporting clients who use the information to make reproductive decisions. In this case the concept of nondirectiveness describes the process of genetic counseling more so than the overarching ethical principle. Some authors claim that nondirectiveness in genetic counseling arose in opposition to the eugenics movement. Resta points out that many of the medical geneticists writing about the process of genetic counseling in the 1950s used the term nondirective but then also described eugenic ideas about the practice (9,10). It is evident from the literature that certain supporters of nondirectiveness were not opposed to eugenic practices. Thus, such claims about nondirectiveness may be unfounded (4,11).

The general source of the term nondirectiveness predates genetic counseling by about two decades. Dr. Carl Rogers, a prominent psychologist, used the word to describe his theory of psychotherapy (12). By 1951, however, Rogers had come to describe his theory and practice as client-centered. This clarification in his terminology acknowledged the presence of directive components to the therapeutic relationship, yet emphasized the focus on the client’s expressed needs rather than the explicit direction of the counselor. Rogerian psychotherapy developed prior to the existence of genetic counseling and in parallel to, not in reaction against, the eugenics movement in the United States. It is intriguing to consider why the profession of genetic counseling adopted as its mantra a term that was rejected early on by the field of psychotherapy. Since its introduction into genetic counseling, nondirectiveness has lead researchers, academics, and practitioners astray.

Genetic counseling has sustained the use of the term nondirectiveness despite its ambiguity. Client-centered theory and practice have offered one useful framework (within limits) of thinking about and practicing genetic counseling. Nondirectiveness has been used effectively to describe a client-centered counseling style not unlike a Rogerian approach. Since genetic counseling has evolved as a clinical and atheoretical practice, it has borrowed ideas from its theoretical neighbors. In a different sense, genetic counseling has long recognized the lack of desire or ability to make reproductive decisions for others. It has emphasized autonomy and voluntariness (13,14). Genetic counseling embraces a certain hands-off approach to sensitive issues of life and death that are entwined in reproductive decision making. This has proved to be
a more comfortable stance for genetic counselors than entering into the difficult and sticky terrain of directing people in their childbearing decisions that involve genetic risk. Rather than as a reaction against eugenics, perhaps nondirectiveness has been sustained by an abhorrence of eugenic practices. Some would argue that it might also serve to shield practitioners from confronting difficult aspects of reproductive genetic counseling.

INTERPRETATIONS AND IMPLICATIONS OF NONDIRECTIVENESS

Nondirectiveness as a Guiding Ethical Principle

There have been at least four different, yet overlapping, meanings of nondirectiveness expressed in the literature. Most often, nondirectiveness has been used to mean a desire to uphold the personal nature of reproductive decision making. Nondirectiveness in this sense represents an underlying value or ethical principle of the profession. Genetic counselors in the United States have emphasized the principle of nondirectiveness conceptually in their code of ethics: "Genetic counselors strive to enable their clients to make informed independent decisions, free of coercion, by providing or illuminating the necessary facts and clarifying the alternatives and anticipated consequences (15, p. 41). Yet as a value it does not readily translate into a way of practice or a specific goal. It is difficult to assess whether an individual or couple has made a "good" personal decision. How does a genetic counselor promote the decision-making process within an ethical framework of nondirectiveness? Clients experience many influences on their reproductive decisions. Exclusively personal or autonomous decision making is difficult, and not necessarily uniformly desirable, to achieve. Yet it is important that providers not assert undue influence on the reproductive outcomes of their clients. This is a blatantly eugenic goal and contradicts the desires of most geneticists and genetic counselors internationally (16). Kessler points out that even when there is an explicit goal to discourage certain reproductive outcomes (e.g., in a country that supports such practice), a significant number of clients ignore the advice (17). It is unclear that it is necessary for professionals to completely withhold advice from clients. Yet much of the international genetics community, and in particular, genetic counselors in the United States, Canada, and the United Kingdom, finds the notion of advising people directly on their reproductive choices to be loathsome. It is difficult to know or to appreciate the values, resources, thought-processes, and ideas of another person sufficiently to provide advice about having or not having children who may be affected with a certain genetic condition. The truth is, most people struggle to understand what choices they would make for themselves, let alone know better for another.

Genetic counselors need to be exquisitely self-aware and not harbor personal opinions of what constitutes a life worth living. If they do, they must be honest with themselves and disclose to clients that they may hold beliefs that children affected with certain genetic conditions should not be born. This differs from stated goals to enhance personal choice for clients. Yet it is more honest than undisclosed potential agendas. Most counselors, who also work with children and families affected with genetic conditions, serve as advocates for those with special needs as children or who are disabled as adults. As a profession they value diversity and often enter the field of genetic counseling concerned about genetic conditions and how society views disability.

Medical genetics services, such as triple screening for neural tube defects and carrier screening for recessive or sex-linked genetic conditions, may have the more or less explicit goal of reducing the number of individuals affected with genetic conditions (18–20). Cost–benefit analyses to justify such programs may be based on an assumption that a significant number of affected pregnancies will be aborted. In this case the genetic counseling that accompanies such practices may have values that are in conflict with the intention to reduce the incidence of genetic conditions. Genetic counseling may strive to help the individual make the best personal decision, yet the goal of the program may be to abort affected fetuses. Genetic counselors may find themselves caught in a dilemma between professional values that emphasize personal autonomy and programs that are justified by social policy to improve the health or well-being of the populace. If counselors uphold a nondirective ethic, then they should not paradoxically endorse genetics services that have a goal of preventing the birth of individuals who will be affected with a genetic condition. Genetic counselors should and do endorse services that emphasize informed and autonomous choice in reproductive decision making. An example is the choice about whether to undergo amniocentesis to determine the chromosomal status of a fetus. Nevertheless, aspects of service provision (e.g., assuming the outcome of the decision to undergo testing by scheduling the amniocentesis to follow the counseling session) do not always promote the genetic counselor’s role to ensure personal choice about testing.

A challenging aspect of an ethic of nondirectiveness is not so much the goal to refrain from explicit influence on reproductive decisions, as it is the potential for more subtle and unintended (even unconscious) influence. Such practice may occur when a genetic counselor harbors a belief that a certain reproductive outcome is most desirable for a person or couple. But rather than state the bias outright, the counselor’s approach is influenced by her or his beliefs. This would be an ethically directive approach even if the counselor did not intend to provide direction to the client.

When counselors successfully manage to facilitate the client’s decision making without influencing the outcome, the process is flexible and difficult to operationalize. Counseling is inherently directive, as is providing education to ensure understanding about the options. Genetic counselors have no standard of practice to consistently uphold an ethic of nondirectiveness. Counselors recognize that the type of information they provide and how they present it may influence decisions (21,22). An ethical principle should translate into an effective mode of practice. White has proposed a counselor–client dialogue as a working description of the process (7). The practice is to facilitate client centered reproductive decision making, within
an ethical framework of nondirectiveness. As a guiding principle this ethic would suggest a process of genetic counseling that emphasizes the values and beliefs of the client, but that tolerates the direction offered by a competent counselor who does not preconceive a decision for the client. In order to further clarify the underlying ethical principles of genetic counseling, the field may need to differentiate itself from other genetic services whose goals (such as abortion of affected pregnancies) are inconsistent with the values of the profession.

Nondirectiveness as a Guiding Policy on Genetic Testing

Nondirectiveness also has been used to describe the concept of not denying access to genetic testing. This definition relates to genetics health policy and access to services. It is a practical one, although it has overlap with the previous definition in its intention to uphold reproductive freedoms. In this case genetic counselors are reticent to deny access to any genetic test that an individual or couple may request (even one that puts a pregnancy at risk) provided that there is understanding about the risks and benefits of the test and its potential outcomes.

Historically much of genetic counseling has addressed risk for serious conditions, with the exception of certain mild birth differences (such as a deformed lip) and sex chromosome "anomalies" (such as Turner syndrome). Counselors offer genetic testing to determine whether a fetus will be affected (prenatal) or whether a couple may be at increased risk (for having an affected child). One survey has suggested that the majority of genetic counselors, internationally, offer prenatal diagnosis (or a direct referral) for sex selection (23). This is worrisome when one considers that genetic counseling originated from a desire to help people grapple with difficult dilemmas about serious genetic conditions or birth defects. Genetic counselors, as represented by the U.S. professional society (NSGC), uphold a moral right to reproductive freedom (24). The majority of practitioners believe that if a woman (or couple) has consented to prenatal testing by considering the relative balance of risks and benefits, she should be offered the opportunity to determine the sex of the fetus, even if she desires to abort a fetus of undesired sex. Such a finding bodes poorly for the future of genetic testing, when prenatal tests may be offered for physical or personality traits. Will genetic counselors, in the name of nondirectiveness, offer prenatal testing for anything a couple desires as long as they are informed?

In this regard, the meaning of nondirectiveness has caused the profession of genetic counselors to be passive about taking a stand on what tests ought to be offered. There have not yet been professional guidelines written by U.S. genetic counselors discouraging certain prenatal testing. Within NSGC there are position statements and a resolution on genetic testing or screening, for instance, one exists on prenatal and childhood testing for adult-onset disorders (25). It states that while such testing is discouraged, each case should be considered individually and counselors should decide whether to offer parents testing of their children on a case by case basis. This leaves the judgment of reasons, fitness, and values of the client up to the counselor. While inherently flexible and accounting for individual differences, it neglects to take a clear stand and puts counselors in the position of practicing inconsistently. It leads to confusion for the profession. In response, members of the genetic counseling community published a substantial position statement on the genetic testing of children for adult onset conditions to more clearly state a testing policy (26). While it is unlikely that there are many moral absolutes in reproductive decision making, an insistence on nondirectiveness has stymied the process of policy making in prenatal genetic testing. With the promised onslaught of new genetic tests, reproductive counselors seem to be prepared to offer testing for any indication. In the name of nondirectiveness, genetic counselors have avoided their professional and moral obligations to take a stand on the appropriateness of certain types of prenatal testing.

The approach to reproductive genetic testing, "anything goes as long as the individual has had pre-test counseling," predicts that counselors will play less of a role in establishing genetics health policy. Yet genetic counselors may be one of the most important groups of professionals to be involved in helping to establish guidelines or policies about what testing may not be an appropriate use of resources or may be morally reprehensible (27). Do genetic counselors advocate for the use of prenatal testing to potentially abort fetuses found to be at somewhat increased risk for adult-onset cancer, for instance? Worse yet, for a slightly lower projected adult height? The role of testing gatekeeper may be an important one for genetic counselors in the future. Yet nondirectiveness has been misinterpreted to imply that any genetic tests that are technically feasible should be offered. In the name of nondirectiveness, counselors refrain from judging the choices of their clients. In doing so, genetic counselors may be washing their hands of the responsibility to offer morally, not to mention economically, responsible reproductive testing options.

Rather than interpreting that nondirectiveness holds no opinion on genetic testing, reproductive genetic counselors ought to offer genetic testing only for serious conditions that may significantly impede an individual's ability to achieve quality of life. While there is no consensus on what constitutes a serious genetic condition (28), this should not dissuade genetic counselors and other providers from establishing responsible genetic testing services and genetics health policy (29,30). This misunderstanding of nondirectiveness has led to a significant lost opportunity and an ongoing need for the professional practice of reproductive counseling.

Nondirectiveness as a Style of Communication

In contrast, nondirectiveness has been construed as a style of communication within the practice of genetic counseling (31,32). Genetic counseling has been described as a value-neutral encounter despite awareness that any human relationship is value laden. The mis-notion of value neutrality has further confused the issues of nondirectiveness (33). In communicating genetic information within genetic counseling, there are many directive components. In an educational relationship, the person with
the information has more power and there is an inequality to the relationship (1). The way the information is conveyed and the amount of information given may be quite directive. Genetic counselors lead, guide, and even advise their clients. Each of these is a directive process. Genetic counselors strive to give complete and balanced information, but it is human nature to be inconsistent and influenced by individual experiences. This might be described as directive practice as well.

This interpretation of nondirectiveness implies information should be conveyed in a nonleading way. Studies that have been conducted to assess use of directive language have concluded that the process is directive (30). While such outcome studies are necessary and valuable for determining what happens in genetic counseling, they seek to document a nondirective psychoeducational practice. It is an unattainable paradox.

In a desire to use nondirective language to communicate, genetic counselors may seek to use words that are ambiguous. Such avoidance of direct language may not be useful to clients who are often seeking not only information but also advice on how to use it or how to make meaning of it. The irony of the use of vague language is that expert communication of complex genetics information is often heralded as a prominent goal of genetic counseling. A nondirective intent has guided counselors into inexplicit use of language that could otherwise make genetic concepts and their implications more obvious to clients. This use of nondirective communication has led to process studies that have shed light on this perplexing notion of genetic counseling (31,34). Conclusions have been drawn that counselors are directive in a manner that implies they are undermining a guiding ethical principle. In fact they are merely communicating as professionals do, using language that is often directive and in a manner that may be directive. While there is merit in research toward understanding how an ethical principle such as nondirectiveness translates into practice, the mode of communication is only one component of a complex dialogue within a relationship of influence.

Without guidance on the adaptation of an ethic of nondirectiveness into practice, counselors have assumed a nonjudgmental approach that also involves noncommittal or evasive communication around difficult issues. This minimization of an ethical principle has led to one outcome counselors seek: clients who have not been explicitly directed in their reproductive decisions. But it has also led to not providing clear messages about the implications of the information, and perhaps even not facilitating "good" reproductive decisions. For instance, Wertz and her colleagues found that in the majority of prenatal genetic counseling sessions they studied, abortion was not mentioned (35). Since it is the only intervention a couple could choose to take for the vast majority of conditions tested for, it should be prominent in discussion about the potential usefulness of prenatal testing. If nondirectiveness had been uniformly adopted as an ethical principle that supports a client-centered counseling process, rather than a communication style, word choice and tone would be considered less significant than the components of dialogue within a therapeutic relationship.

Nondirectiveness as a Theoretical Basis of Counseling Practice

This point segues into a further interpretation of nondirectiveness, the intent to provide client-centered counseling. This definition is not dissimilar to that of Rogers's theory of psychotherapy. In this regard, nondirectiveness represents a reasonable and responsible goal for genetic counseling. It heralds the role of the client as central and the goal, can be achieved (1,36). In this venue nondirectiveness provides a model for genetic counseling that can uphold an ethic of personal reproductive decision making. But nondirectiveness should not be used to describe both the process of counseling as well as the underlying ethical framework or the existing confusion will pervade.

In describing genetic counseling as a psychoeducational process, the psychological or therapeutic goal is to explore the meaning that the genetic information has for clients. This is a client-centered approach that focuses on client values, beliefs, ideas, and desires. The process by which this is achieved varies but the client's agenda and needs are paramount. As Rogers previously discovered, the term nondirectiveness in this case compounds the confusion, since many strategies used by the counselor might be described as directive. Yet they are executed with the client in mind. For instance, the counselor may help the client to set an agenda to explore implications of the information in a way that is personal, useful, and lends itself to decision making. The counselor may be directive in helping a client determine what may be reasonable to try and accomplish in one or two sessions. While these behaviors are directive, they do not override the needs of the client. Rather, they represent the counselor's expertise that may be used to enhance the effectiveness of genetic counseling. The client's needs are the ones addressed, but the client is not left to talk randomly without focus on the problem or issue at hand. Without such structure, a session would never become therapeutic. This is only one example of directive practices of counselors that do not undermine a client-centered approach.

In this more appropriate use of nondirectiveness the term remains problematic and should be replaced with client-centered genetic counseling. In much the same way nondirectiveness did not accurately depict the therapeutic approach proposed by Rogers, it has lead genetic counselors to largely ignore the need to engage actively with clients in order to address their concerns. Transcripts of genetic counseling sessions indicate that counselors practice inadequate counseling skills to accomplish even a minimally client-centered approach (1,5,31). The mantra of nondirectiveness may have caused counselors to hesitate over using their own best judgment about people's ability to make good decisions for themselves, to grow from difficult experiences, and to cope and adjust. In the name of nondirectiveness, many counseling opportunities have been lost in genetic counseling. An active dialogue about options, alternatives, resources, strengths, and outcomes within a therapeutic relationship may best help clients (3,6,7). Such a dialogue is likely to have many directive statements in it but does not direct the client toward a certain outcome in a coercive or even persuasive way.
Although the various uses of the term nondirectiveness have been problematic for the profession of genetic counseling, the pervasiveness of the concept of personal autonomy in genetic reproductive decision making sets the practice apart from the majority of medical services. The ethical principles of autonomy and beneficence in reproductive decision making, the need for thorough informed consent for genetic testing, and the value of human diversity and the lives of those affected with disabilities are crucial to reproductive genetic counseling. And the few outcome studies that have been conducted suggest that reproductive genetic counseling clients are satisfied with the service. They like their genetic counselor and are grateful for the time spent teaching them genetic principles (37). From a process and outcomes perspective, clients are likely to be best served by a psychoeducational approach that includes a client-centered or cognitive, theoretically based practice. This therapeutic process and its desired outcomes of self-determination, feelings of personal control, and restored self-esteem have yet to be studied (38). To achieve them, a counselor may be directive and conduct process studies that investigate how directive she or he is seems counterproductive. Studies are needed on the most effective therapeutic approaches in genetic counseling, to observe how successful they are in achieving desired outcomes. Research would be facilitated if genetic counselors embraced such a therapeutic approach, and if consensus could be achieved on the goal of restoring feelings of personal power to clients and on outcomes of the process that can be systematically measured.

Nondirectiveness in Practice

In the most common reproductive genetic counseling example of a couple learning that their fetus is affected with Down syndrome (due to an extra chromosome 21), genetic counseling is the process through which the couple can determine what the condition may mean for their lives. Down syndrome cannot be “repaired,” although some of the symptoms can be treated. The child will be mentally retarded, although to what degree is unknown. The couple may continue the pregnancy as planned or have an abortion. This is an agonizing decision even for couples who initially feel confident about what they would do in such circumstances. In facing the situation couples often take into account their expectations of parenthood, family life, economic resources, previous experiences with persons who have Down syndrome, opinions of family and friends, spiritual beliefs, social influence and expectations, and so on. Decisions about a pregnancy are complex, deeply personal, and irreversible. Important aspects of the decision may even be intangible or elusive to the couple themselves.

A genetic counselor in this situation seeks to establish an empathic connection or a therapeutic bond with the couple in order to help them make personal meaning of the information about Down syndrome. The counselor may strive to identify resources useful to the couple in making the decision so that they can live with their decision (one way or the other) in the years to come. A therapeutic approach focuses on enhancing self-determination and perceived personal control. Couples are helped to recognize that they have the strength to make such a difficult decision and that they have made other decisions successfully in the past. The counselor works toward facilitating the decision-making power of the couple in addressing their needs and concerns. This process may be described by some as nondirective counseling. Yet it is more appropriately described as client-centered and personally empowering.

The example of a client or couple asking the counselor what he or she would do in the same circumstances is often used to illustrate nondirectiveness in genetic counseling. Common responses by genetic counselors may be:

- “I am not in your situation so I couldn’t possibly know what I would do.”
- “Other people in your situation have chosen to continue the pregnancy, while others have had an abortion.”
- “There are no right answers, I am here to help you make the best decision for yourself.”
- “I will support any decision you make.”

Evasive answers such as these do not address the concerns of the client. The client is asking for advice because she has not received the help she needs to make her decision. It is unlikely that she is literarily handing over responsibility for the decision to the counselor (although a minority of clients may do so). Nor is she likely to mimic the choice of the counselor in order to solve her dilemma. However, all too often counselors neglect to work toward exploring and understanding where the client’s anxiety and concerns come from in an effort to best help her with the decision. Kessler reminds genetic counselors that if the clients are frequently asking this question, there is something fundamentally flawed about the process (4). There are many respectful and considerate ways to address this question without abandoning the client in a time of great need. They challenge genetic counselors to fully experience with clients some of the hardest decisions of their lives. It takes a lot of hard work and direction on behalf of the counselor. A nondirective mode of practice misinterpreted is a missed counseling opportunity and at its worse an abandonment of a client in need of help.

Summary

Nondirectiveness is a term to be reserved for an ethical principle of practice in reproductive genetic counseling. It emphasizes the importance of autonomy in genetic reproductive decision making. As a guiding principle, nondirectiveness provides a moral framework for providing client-centered counseling. Reduced to merely how a counselor communicates or to a lack of health policy on the use of genetic tests, nondirectiveness is an intellectual concept. Its counterpart, direction, is an essential aspect of effective client-centered counseling that supports informed reproductive choices involving genetic risk.

See other entries GENETIC COUNSELING; see also REPRODUCTION; ETHICS entries; REPRODUCTION, LAW; REGULATION OF REPRODUCTIVE TECHNOLOGIES.

**REPRODUCTION, LAW, IS INFERTILITY A DISABILITY?**

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**OUTLINE**

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**INTRODUCTION**

Infertility is defined as the inability to conceive a child within a period of one year. There are many causes of infertility, and it may be attributable to either partner or a combination of factors related to both partners. Infertility can be costly and time-consuming to treat, and success is not guaranteed or even probable in many cases. The costs to infertile individuals and couples can involve money, time, and physical and mental health.

Working women and men who are infertile want to keep their jobs, even if they require leave time or scheduling changes for fertility treatment. The spouses of infertile partners also may require workplace accommodations to participate in fertility treatment. Both individuals want to have health insurance coverage that provides reimbursement for costly fertility treatments. For these reasons it is important whether infertility is considered a disability under federal or state disability discrimination law.

The Americans with Disabilities Act (ADA) of 1990 (1), the Rehabilitation Act of 1973 (2), and many state laws prohibit discrimination against individuals with disabilities by employers and providers of services, which may include health insurance. It is essential to