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# Privacy as a Social Concept

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UNIVERSITY OF CALGARY

Privacy as a Social Concept

by

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## **Abstract**

In this thesis I critically examine the traditional account of privacy as a negative right of non-interference and offer instead an alternative framework based on obligations and trust.

Privacy is most often described as a value best protected as a right, more accurately as a negative right of non-intrusion. This means that privacy is associated with the private sphere: the individual should be left to decide when he wants to be alone and what he wants to share with others. I begin with an examination of three different distinctions between the public and the private and then I go on to examine two models of privacy: the separation model, where privacy consists of restricted access, and the control model which consists in individual control over certain aspects of one's life. I argue that these models fail to meet many privacy concerns. This becomes most apparent when examining the privacy challenges associated with information technology and biobanks.

My alternative account of privacy recognizes how deeply privacy is embedded in social norms and structure. Privacy does not apply to situations where an individual is in isolation, but rather depends on relations to others. This means that privacy is a relational concept: it is an important value in structuring relations between individuals or social institutions. I argue that the framework of rights does not provide an appropriate framework for protecting privacy. Instead, I introduce a framework based on obligations and trust, inspired by Onora O'Neill's account of perfect and imperfect obligations.

## **Acknowledgements**

The topic of privacy has been with me for a long time, and I have over the years made several attempts with fairly long intervals to write about privacy with insufficient success. At the beginning of the year 2011, on a six month sabbatical from the University of Iceland, I decided to make a last attempt to take up where I had left off when working under the supervision of Brenda Baker. After being re-admitted to the doctoral program at the University of Calgary, I was lucky to get Ann Levey as my supervisor. Ann has from the beginning of our work together believed that I had some ideas worth exploring and she has been a true supporter all the way to the very end.

There are many people I would like to thank: friends in Calgary and Iceland, colleagues and family, people who have given me enormous support, encouragement and help. The list is going to be too long, and fearing I would forget someone important, I am only going to mention those who are dearest to my heart, my parents and my sons, Páll and Jóhannes, who are going to be as relieved as I am to see this work completed. To them I dedicate this work.

*To Páll and Jóhannes*

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## Chapter 1: Introduction

Privacy is a fascinating topic for the ethical theorist and is a matter of ever-increasing practical relevance. But at the same time that privacy is claimed to be an important right, there is a deep disagreement on what constitutes privacy. The conceptual unclarity that characterizes the philosophical literature has generated frustration among many leading privacy scholars, who “feel a sense of uneasiness”<sup>1</sup> when working on the topic, label the privacy literature as a “chaotic world”<sup>2</sup>, describe the subject as “messy and complex”<sup>3</sup>, and find themselves in an “unknown swamp”<sup>4</sup>, dealing with a “conceptual jungle”<sup>5</sup>. The main effort has been to construct a workable definition of privacy that is both narrow and broad enough to capture its different meanings and capable of securing our interest in privacy as a right. In consequence, we have a legion of definitions of privacy and multiple accounts of why privacy is valued. These accounts point to the interests in being let alone, in being free from certain kinds of intrusions, in not having certain information about oneself published, and in being free to make decisions about personal matters, to name but a few. Still the classification of privacy values continues, with ongoing attempts to analyze the concept and with little consensus in sight.<sup>6</sup>

One reason we may find the world of privacy “chaotic” is the vast literature, scattered throughout different disciplines. At least five separate “discourses” have been identified that often talk past one another.<sup>7</sup> These include extensive debate in US jurisprudence, within both

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<sup>1</sup> Gavison (1980) p. 346.

<sup>2</sup> Innes (1992) p. 3.

<sup>3</sup> Nissenbaum (2010) p. 67.

<sup>4</sup> Innes (1992) p. 3.

<sup>5</sup> Solove (2008) p. 196.

<sup>6</sup> See Anderson (2008) Matheson (2008) Nissenbaum (2010) and Solove (2008).

<sup>7</sup> Rössler (2004), p. 2-5 and Rössler (2005) p. 2-4.



tort and constitutional law; the social and philosophical discussion of the public sphere, which conceives privacy in relation to the domain of intimacy, space, and decisions; the critique of feminists of the public-private distinction in relation to the traditional view of the family; the enormous discourse related to the explosive rise of information technology; and the philosophical discourse within liberalism concerning the public and the private.

In the literature it is also traditional to distinguish between at least three domains of privacy: *informational* privacy, *physical* privacy, and *decisional* privacy.<sup>8</sup> My focus will be on the first two: informational privacy and the privacy of space. Informational privacy is not seen as protecting just any kind of personal information but rather sensitive information: information that can harm the individual if published or that he or she does not want others to know for other reasons. In this connection, reference to the public-private distinction is necessary. Informational privacy and privacy of space are often separated from the third kind: decisional privacy. The literature on decisional privacy derives from US constitutional law and the debate on abortions and contraceptives, foreign to many other countries. I side with those who have argued that so-called decisional privacy is in fact a form of liberty rather than of privacy.<sup>9</sup> As a result, questions concerning decisional privacy lie mostly beyond the scope of this thesis.

The earliest definition of privacy was offered more than a century ago by Warren and Brandeis in their influential paper, “The Right to Privacy”, where they argued that privacy is a

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<sup>8</sup> Judith Wagner de Cew identifies three aspects of privacy; informational privacy, accessibility privacy and expressive privacy in De Cew (1997). Anita Allen discusses four dimensions of privacy as being informational privacy, physical privacy, decisional privacy and proprietary privacy in Allen (1997) and Rössler separates three spheres of privacy: informational privacy, local privacy and decisional privacy, in Rössler (2005).

<sup>9</sup> Matthews (2008) p. 132.

right to be let alone.<sup>10</sup> With this definition, Warren and Brandeis set the tone for succeeding debates about privacy, which have been heavily influenced by US legal scholars. There, privacy has been treated as a value that is associated with the private sphere, away from others and best protected within the framework of rights. In this thesis I will reject both elements of that view. Instead, I will argue for understanding privacy as a social concept that has to do with social relations and how we share information and space with one other. This means that privacy must be explained in relation to social contexts and social norms but is not a unified concept. Furthermore I will argue that privacy should be analyzed in terms of obligations rather than rights and that a trustworthy environment is a necessary condition of privacy. Therefore, privacy is not a value that should be associated with solitude or secrecy, but is very much present in all our relationships – how we share space and information, how we respect each other both in the public and private domains.

In the first two chapters of this thesis I will examine traditional perceptions of privacy. Privacy is most often defined as something that we have an individual right to; more accurately, as a negative right of non-intrusion. This means that privacy is most often associated with the private sphere where the individual should be left to decide when he wants to be alone and what he wants to share with others. The philosophical foundation of privacy is most often discussed within the context of liberalism, with a focus upon the public-private distinction with the public sphere being defined in terms of limits to governmental intrusion. However there are several ways of distinguishing between the public and the private, all relevant to the standard understanding of privacy, all of them found in liberal writing on privacy, and often without making the distinction clear. Given how central the public-private

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<sup>10</sup> Warren and Brandeis (1890). According to McCloskey, James Fitzjames Stephens discussed privacy in 1873. However, Warren and Brandeis are usually taken to have “opened the debate”.

distinction is for liberals, it is striking how little attention is devoted to the philosophical analysis of privacy within traditional liberal theory.<sup>11</sup> In chapter 2 I will examine three ways of distinguishing between the public and the private. I will argue that these three distinctions are intertwined and that none of them capture the core value of privacy. Also I will discuss privacy and social norms in relation to the public-private distinction and different societies. When we examine different languages we see that this social aspect of privacy is, for instance, better captured by the Icelandic term for privacy than the English term.

In chapter 3 I will discuss and examine two models of privacy: the *separation model* and the *control model*. According to the separation model, privacy consists in a state of restricted access to the individual: it is a neutral description of being in private. According to the control model, on the other hand, privacy consists in individual control over certain aspects of one's life. Therefore, the distinction between the public and the private is a necessary aspect of the separation model but is referred to only indirectly by the control model.

My criticism emphasizes the social aspect of privacy and how the traditional understanding of privacy tends to overlook the role of social norms: both how important privacy is for different social roles, and how the protection of privacy depends on other people but is not unilaterally defined by individuals. I will emphasize that the concept of privacy has to do with fundamental questions concerning how we share our lives, thoughts and experiences with others. It depends importantly on social norms and social structures; it is in this way a relational concept.

In the fourth chapter I will discuss information technology in order to demonstrate how inadequately both the control model and the separation model meet the privacy challenges that arise in contemporary society. The early paper by Warren and Brandeis is believed to have

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<sup>11</sup> The debate has been driven by legal scholars but there are notable exceptions such as Benn and Nagel.

been written in reaction to instant photographs and mass-produced newspapers, new technologies of that time.<sup>12</sup> A good part of the subsequent literature on privacy can be seen as a reaction to other developments of modern technology, such as the possibility of tapping telephones, taking photographs from a distance, and data mining the internet. The fast-growing media and informational technology not only makes our lives easier but has also opened the door to more sophisticated privacy invasion by surveillance, monitoring and data storing. Furthermore, the development of information technology, along with deeper understanding of genetic information and the existence of big databanks of personal information, presents us with some novel privacy concerns. In these ways, technology has proven to be a moving target, challenging profoundly the traditional framework of privacy. The concerns have less to do with intrusion and more to do with how personal information is stored and used in modern society. More sophisticated surveillance technology is transforming our sense of public space, making the issues of privacy in the public sphere more pressing; “social networking” is even changing our self-understanding of the personal and the private.<sup>13</sup> Whatever the circumstances, privacy issues concern how information can be protected after being handed over to someone – who else may gain access to the information, and how it may be used without potential harm for individuals. This directs us towards questions of trust, both in social institutions and in our fellow citizens.

In the fifth and final chapter I argue that the framework of rights does not provide an appropriate framework for protecting privacy; it is too blunt a tool to capture the nuances of different social contexts. Instead, I will introduce a framework based on obligations and trust,

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<sup>12</sup> Allen (2004).

<sup>13</sup> Nissenbaum (1998), Nissenbaum (2010).

inspired by Onora O’Neill’s account of perfect and imperfect obligations.<sup>14</sup> O’Neill’s approach moves the onus of respecting privacy from the one who claims it as a right to those who ought to respect it, and takes into account the broad interests associated with privacy. The framework of obligations focuses our attention upon shared values and relations between people, rather than upon the values of individual persons considered apart from others. O’Neill also brings in the importance of not being deceived, manipulated or coerced: principles that lurk behind the scenes in the literature on privacy violations, since invasions of privacy make us vulnerable to deception and manipulation. This discussion will show how we need to think of privacy in the context of relations between people and of trust.

Understanding privacy as being based in obligations rather than in rights, in a world where morality is importantly rights-based, may sound like giving up on privacy. Still, this thesis defends privacy as an important value in human lives; it is a value attaching to human relations. Moreover, I hope to show how much confusion and frustration derives from trying to force the interests of privacy into a rights framework. Therefore I think it is worth arguing for privacy as a value rooted in obligations and trust, because I truly believe that a society that values privacy in its social relationships is a better society than a society which ignores privacy. This theoretical debate is a part of a larger one, namely whether morality is best seen as rights-based or not and—not surprisingly—I agree with those who have argued that rights-based morality is impoverished.<sup>15</sup> Therefore I propose what I believe to be a more accurate account of privacy that recognizes its social value within the varied contexts of social relations.

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<sup>14</sup> O’Neill (1996).

<sup>15</sup> Raz (1984).

## Chapter 2: The Public and the Private

Privacy is traditionally seen as resting on an opposition between the public and the private. Since privacy is conceptually related to the private this understanding has a strong intuitive appeal. According to this view we need to protect our privacy against intrusion or the demands of others. In this chapter I will argue that this view is based on weak grounds for at least two reasons. On the one hand there are numerous ways of distinguishing between the private and the public with different senses of the private, none of which will independently map onto privacy, nor do these understandings of the private do so collectively. On the other hand the conceptual relations between the private and privacy are arguably a function of English etymology and do not necessarily translate into other languages, as we see when we examine Icelandic language, where the relation with social norms and structure is important.

In this chapter I will look at the relations between privacy and the public-private distinction and furthermore what is constituted in the relation between privacy and the private.. This I will do by looking at three ways of making the distinction between the public and the private, all of them relevant for understanding privacy even though none of them capture it exactly. The first is the liberal distinction where the private sphere of non-interference is contrasted with the public sphere of rightful interference. The private sphere is the sphere where citizens organize their lives according to their own beliefs and ideas: it is where they develop their relationships with others, choose their ways of living, and pursue their own goals.<sup>16</sup> This broad notion of the private includes the social sphere or the civil society. In

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<sup>16</sup> Kymlicka (2002) p. 288-289.

contrast the public is the political sphere or the state, with public regulations and its main function to protect individual freedoms in the private or civil society.<sup>17</sup>

The second distinction is between public and private space, or that which is accessible or open in contrast to what is inaccessible or hidden. There are places and spaces that are public in the sense that everyone can be physically present in them. In contrast we have spaces with restricted access. This is the view that privacy needs a private space or a shelter from the demands of intrusive society. I will discuss briefly several different ways of describing the importance of private space. One of the problems with associating privacy with restricted space is that it obviously excludes the possibility of privacy in public. However, as will be discussed in this thesis there are many ways we want to enjoy privacy in public space.

The third distinction centers around the private and the public as intimate or non-intimate – things that we are required to keep hidden or secret and not expose in public. This distinction centers on activities or things that are regarded as private, and in most societies there are social norms that protect the public from exposure of private things or activities. In most societies people expect to be able to move around in the public space without being exposed to personal activities or “private parts”. Not all such restrictions on public exposure are seen as capturing privacy.

While it is helpful to separate these three different distinctions, examination of them shows that they are in many ways intertwined. Most obviously, private activities blend with private space: we prefer to do private things in private space hidden away from others. In many cases writers do not make the effort of separating these two distinctions in any systemic way, as will become apparent in my examination, for instance, of a paper on privacy by Nagel

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<sup>17</sup> Kymlicka (2002) p. 388.

where he refers to all three distinctions of the public-private distinction without drawing attention to their different underpinnings. Furthermore the discussion will show that none of these distinctions capture the core meaning of privacy either independently or collectively.

As I will argue privacy is a value that is important in social relationships but not a value of isolation or secrecy. Therefore the idea that privacy originates from a private sphere where individuals are away from others is leading in a wrong direction: it overlooks the relational aspect of privacy and its grounding in social conventions. Even though Nagel argues that privacy is importantly related to the public-private distinction, he acknowledges how privacy is protected by social norms when he points out that exposure of private matters does not depend solely on the individual but also on social norms and practices. This will become an important theme in this thesis.

When we explore privacy in different cultures and languages we see that the conceptual connection between privacy and the private is not absolute. I will close the chapter with a brief discussion of how “privacy” translates into Icelandic. Then we see that the Icelandic term does not refer to a private sphere but rather to a sanctuary that can be available in many different relations. Furthermore the Icelandic term also has strong reference to social norms and practices.

### *2.1 The private sphere of non-interference*

The private sphere has been primarily important for liberals as the locus of human flourishing. The liberal tradition defines the boundaries between the private and the public in terms of state interference and the limits of coercion.<sup>18</sup> Accordingly, the public sphere, with its public institutions, is subject to public rules and regulations; it is the sphere where we discuss

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<sup>18</sup> Weintraub describes this distinction as the liberal-economist model, Weintraub (1997) p. 7.



collective interests or general principles that can be applied to all. The private sphere is, on the other hand, the locus of human development, where citizens organize their own life according to their own beliefs and ideas. This is the sphere of individual freedom.

Mill argued for the boundaries between the public and the private in relation to activities, and that an individual is “not accountable to society for his actions, in so far as these concern the interests of no person but himself”.<sup>19</sup> This means we are not required to explain or justify the choices we make in our private lives. As a utilitarian, Mill drew the boundaries between the public and the private in terms of the harm principle; namely, that people are free to conduct their lives in any way possible as long as they do not harm others.

This focus on the individual in contrast to collectivity takes on many forms. We talk about public and private interests, public and private morality and public and private roles to take a few examples. Take for instance the difference between public and private roles. Liberals stress that the public roles we serve are only public, but do not define our whole life. A judge, a politician or a professional is only accountable for what he says or does when he is “on duty”. What a judge says on the bench has public significance, but not what he says in his club or with close friends.<sup>20</sup> This separation between public and private roles allows us to pursue different interests or even morality in public than in private. Furthermore we can decide to give a different appearance of ourselves in our public role than we do in private.

One branch of the privacy literature focuses on decisional privacy, or the individuals’ decisions about their private issues. This concept generates from the understanding of the private sphere as non-interference which has developed within US constitutional law. Here we have a debate on contraceptives and abortions in cases such as *Griswold v. Connecticut* and

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<sup>19</sup> Mill (1947) p. 95.

<sup>20</sup> Benn (1971) p. 22.

Roe v. Wade. The appeal to privacy has been based on the idea that individuals should be able to make decisions on private issues such as to use contraceptives or have abortions. This is because these decisions “are so intimate and personal that people must in principle be allowed to make these decisions for themselves, consulting their own preferences and convictions, rather than having society impose its collective decision on them”.<sup>21</sup> These kinds of arguments have also been extended to end-of-life decisions.<sup>22</sup> Decisional privacy is more about freedom to make decisions about certain things, or freedom from authority, rather than privacy.

Defining the private in terms of private affairs, outside the scope of state interference, suggests a broad understanding of privacy including most aspects of social life such as economy, education and culture - what is often referred to as the civil society.<sup>23</sup> Drawing the distinction between private activities of individuals and the state presupposes at least two things. First, it rests on the premise that there are activities that are private and distinct from the public. For instance we are at liberty to make personal choices about reproduction, family planning and many lifestyle issues. Still, it is often hard to define when some of our activities concern others or may cause harm to others – it may depend on circumstances rather than content. Information concerning our health is normally regarded as private; we should be able to control who has access to our medical files. However, in some cases we may be held accountable for giving information concerning our health to our relatives, sex partners, or even to authorities; this is most apparent if we have infectious diseases that may put others at immediate risk.<sup>24</sup>

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<sup>21</sup> Dworkin (1993) p. 106.

<sup>22</sup> Dworkin (1993).

<sup>23</sup> Moon (1993) p. 36-37.

<sup>24</sup> Health information will be discussed further in chapter 4.

Second, the liberal tradition begins with the individual and his or her interests. However, very often we are a part of a social web where our interest is intertwined with others', both our family's and other community members'. Anita Allen explores these issues in her book *Why Privacy isn't everything* and discusses many cases where we are held accountable to others for our personal matters, such as in the case of drug use or sexual behaviour in private circumstances of our family and homes.<sup>25</sup> Her point is not that we are always accountable for these matters, far from it, but rather to demonstrate how these issues are in reality very complex and cannot easily be categorized as either private or public; it depends on contexts and circumstances.

This broad understanding of the private does not match with the private as private space of restricted access. On the contrary, what happens in the private sphere of religious activity, or within the family is very much accessible to others. Liberals have been criticised extensively by feminists for their ambiguous views on the family and its place within their public-private distinction. Feminists, who argue that gender inequality is rooted in the domestic roles of women, have criticized liberals for conflating the idea of restricted access with private activity in the sense of non-interference.<sup>26</sup> Liberals have tried to accommodate the feminists' criticism and they have argued the liberal distinction between the public and the private is not a distinction between public and personal space, but about the nature of activities. Therefore, it does not matter where these activities take place. J. Donald Moon argues for instance that since liberals are not making a distinction between public and private space they can regulate domestic violence and child abuse: "Inasmuch as human rights can be violated in

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<sup>25</sup> Allen (2003).

<sup>26</sup> Landes (1998). The distinction between the private and public as between the household and the public activity goes back to Aristotle. See also Kymlicka (2002) p. 389.

the personal sphere, the liberal agrees that the personal is the political”.<sup>27</sup> Therefore liberals are primarily occupied with private activities or private kinds of things rather than private space of restricted access. It is outside the scope of this thesis to address the feminist criticism of the private and privacy in any detail. What is worth pointing out is that feminists draw attention to the household or the marriage that is both a social institution and belongs to the private space of restricted access.

Although liberals argue that their notion of the private cuts through the private space, or is not about private space, we see that most rules regulating parental care of children and protection of women have been slow in coming. This is evidence of how reluctant even liberals are to enforce regulation in the private space of the household. This is partly due to the fact that they do not address the issue of the domestic household but simply assume, as Moon does, that the liberal distinction has the tools to address the issue without any attempt to address the subordination of women and children within the home. As Kymlicka points out, even though the gendered distinction between the public and the domestic is not invented by liberals this “sharp separation between the (female) domestic world and the (male) public world” is “inherited” by liberals and endorsed in their theory.<sup>28</sup> And as we have seen, there is typically no attempt to address how gendered inequality affects justice or rights in the public sphere.<sup>29</sup>

We see from the above discussion that the liberal distinction is not clear cut and separating what belongs to the individual v. the collective is not straight forward. Also this distinction is broad and its main role is to secure individual freedom against state interference rather than privacy. The privacy interest associated with this distinction is closely related to

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<sup>27</sup> Moon (1993) p. 152.

<sup>28</sup> Kymlicka (2002) p. 390.

<sup>29</sup> An exception is of course Mill on the subordination of women.

individual freedom and hence many have argued that decisional privacy is simply a conflation between privacy and liberty. Furthermore privacy interests that have to do with more informal relations between individuals cannot be addressed by this distinction; it fails therefore to capture most of the interesting cases of privacy.

## *2.2 Public-private space*

One basic or fundamental distinction between public and private is between what is hidden or withdrawn and what is open or accessible. We usually regard parks, streets, shops and buses public in the sense of being accessible and open to everyone in contrast to places that are closed off or with restricted access.<sup>30</sup> This understanding of the public-private distinction is most often associated with privacy.<sup>31</sup> However there are not many attempts in the literature to spell out what characterizes such a private space further. In his analysis of privacy, Stanley Benn points out how differently we act when we believe we are being observed and thus he argues that we need a space where we are free to be ourselves and observers can be excluded.<sup>32</sup> Benn, in this context, refers to private as private space, where we can develop our true nature or show different sides to our character than we do when we are in public space.

This view has become the prevailing view within the privacy literature. It is traced back to the Romantics, who saw the private as a personal retreat where the individual can contemplate, experiment and regenerate strength.<sup>33</sup> According to Kymlicka the Romantic perception of the private space was originally presented in opposition to “liberal glorification of society”.<sup>34</sup> However, as Kymlicka discusses, and Benn’s argument shows, the Romantic

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<sup>30</sup> Habermas (1994).

<sup>31</sup> Weintraub (1997) p. 4.

<sup>32</sup> Benn (1971) p. 24. This point from Benn will be taken up later in chapter 5.

<sup>33</sup> Kymlicka (2002) p. 394, Geuss (2001).

<sup>34</sup> Kymlicka (2002) p. 394.

distinction has been endorsed by liberals. For liberals private life not only constitutes civil society but the view of the Romantics where the private life is a “personal retreat from that ordered social life.”<sup>35</sup>

Iris Marion Young and Beate Rössler define private space and make an attempt to characterize the private space and give it the “material meaning of home”.<sup>36</sup> They do not have in mind the household, with its gendered role, but the basic space we can control access to and a space we can arrange according to our needs. Young identifies two levels of importance of the home. On the one hand it is the dwelling space which supports our personal habits and general needs; it is importantly our own space and supports and displays who we are. On the other hand, it is the space where we have our things, those items we have collected that have a special meaning to us.<sup>37</sup> Young, who is primarily discussing the situation of old people who need extended care, argues that such a space or a room of one’s own is a “basic element of the value of privacy.”<sup>38</sup>

Jeremy Waldron also discusses having private space in relation to the home but focuses on homeless people.<sup>39</sup> Waldron analyzes the important relation between private space and individual freedom and refers to the private space as the fundamental interest of human beings. We are embodied beings and we take up space and thus it is necessary for us to be somewhere. Anyone who owns or for other reasons is entitled to his or her own private space has a right to be there. Other people need the owner’s permission to enter the space. People who do not have homes do not have a private space to do the things we are supposed to do there. If homeless people are not free to do these things in open public spaces, or there are no public spaces

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<sup>35</sup> Kymlicka (2002) p. 395. Geuss (2001).

<sup>36</sup> Young (2004) p. 168, Rössler (2005).

<sup>37</sup> Young (2004) p. 172-174.

<sup>38</sup> Young (2004) p. 169.

<sup>39</sup> Waldron (1991).

available for them, they do not have any place for these activities. Therefore they are not free to do these things, or are “utterly and at all times at the mercy of others”.<sup>40</sup> Therefore people who do not have a home are robbed of private activity. Waldron says: “A person who is not free to be in any place is not free to do anything; such a person is comprehensively unfree”.<sup>41</sup> Waldron, unlike Young, does not mention privacy in relation to private space. Rather he connects the private space with freedom and therefore refers back to the classical distinction between the public and the private as non-intrusion; an important aspect of freedom is to have private space within civil society.

Still another way of connecting the distinction between public and private space with privacy is presented by Nagel. In his paper “Concealment and Exposure” he is primarily interested in protecting privacy against unwanted exposure in the public space and hence individuals must have private space.<sup>42</sup> Although he discusses primarily sexual issues, such as exposure of nakedness and exposure of sexual activity, his argument is meant to have a wider relevance for a variety of private issues. Nagel discusses public exposure in relation to a core issue of liberal theory of creating community, where people with diverse values and interests can share their lives without compromising their personal autonomy. For liberals it is important to be able to control the private: that people can choose what to share with others, and are not exposed against their will. Nagel is referring to privacy as individual control; we are entitled to hide things from others. This perception of privacy will be discussed in the next chapter.

When discussing privacy in relation to the public-private distinction often writers are referring to more than one way of making the distinction and often without drawing attention

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<sup>40</sup> Waldron (1991) p. 299.

<sup>41</sup> Waldron (1991) p. 302.

<sup>42</sup> Nagel (1998).

to this fact. Nagel seems to be primarily interested in exposure in the public and therefore the distinction between the private as restricted access vs. public as open and accessible.<sup>43</sup> We need closed-off space that will protect us from the public visibility. Unlike in the private setting, with trusting people who are willing or able to understand each others' motives, preferences and explanations, we cannot expect such a sympathetic response in the public. Therefore, in public others are more likely to react with condemnation and disgust rather than sympathy and understanding.<sup>44</sup>

At the same time, Nagel refers to the liberal distinction between the public in relation to state interference as opposed to private activities, when he argues that exposure of private things cannot be dealt with collectively. He argues for instance that there is much more to our character than we are able to show in public – the public sphere is not big or broad enough for individual flourishing: “Each of the multifarious individual souls is an enormous and complex world in itself, but the social space into which they must all fit is severely limited. What is admitted into that space has to be constrained both to avoid crowding and to prevent conflict and offense”.<sup>45</sup> The public sphere does not have the means to deal with the complexity of individuals and individual interests.

Therefore it seems that Nagel is referring to two different conceptions of the public-private distinction, but he does not make the distinction clear, perhaps because he regards these two conceptions of the distinction as intertwined in some respect. The public space of ‘sociability’ where we interact with each other in our daily life is a “sphere of broad and largely unplanned encounter”.<sup>46</sup> This is a different distinction between the public and the

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<sup>43</sup> Nagel (1998) p. 28.

<sup>44</sup> The role of art and literature is to show us the dimensions of individual life to be discussed in public.

<sup>45</sup> Nagel (1998) p. 8-9.

<sup>46</sup> Citation from Roger Scruton in Weintraub (1997) p. 17.



private than that usually associated with liberals; Nagel conflates these ideas of the public as open and accessible and the political sphere of collective interests, never clarifying them. However, these different public domains have different underpinnings as we have seen. The first meaning is public as a space of social interaction; the second meaning is public as the domain of collective interest and state authority. . His focus on sexual activities also refers to the third distinction I mentioned in the beginning of this chapter, the distinction between the intimate and non-intimate.

Before leaving the distinction between private and public space I want to discuss some problems with associating privacy with private space. If privacy is related to private space, we cannot argue for privacy in public. However, as will be discussed in later chapters there are many cases of privacy in public. We put out a blanket in a public park and thereby designate a private space within the public. The distinction between public-private space cannot make a case for privacy in public. As we will see in the following chapters it makes sense to say that we have privacy in public.

Although I make a distinction here between private space and intimate activity, often these two understandings of the private are conflated in the literature. Weintraub for instance argues that one of the two fundamental distinctions between the public and the private is between what is accessible in contrast with what is not. However once he starts explaining this distinction he immediately starts talking about things we are able or entitled to keep hidden.<sup>47</sup> As we have seen, for Nagel privacy is importantly related to having a space where we can keep things to ourselves; it enables people to control for themselves how they appear in the

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<sup>47</sup> Weintraub (1997) p. 6.

public, what they do or do not reveal. But Nagel is also interested in the distinction between the intimate and non-intimate. This distinction will be discussed in the next section.

### *2.3 The intimate and non-intimate. Things to keep private*

Although we regard public spaces as open and accessible to all, nevertheless, these places have certain restrictions and some people may be excluded from these places on the bases of race, age, dress or for other reasons. Furthermore there are in most societies restrictions on what we are allowed to expose in public. Our behaviour within this social domain is guarded by many social norms and conventions, both in relation to what we are not allowed to do in public, as well as in relation to how we should conduct social encounters. These social norms often relate to bodily functions and sexual behaviour.

Many activities regarding bodily behaviour are restricted in the public: we are not allowed to bathe, or take part in sexual activities, on streets or in public parks. These are things we are supposed to do at home or within closed-off spaces. There are norms that protect the public space from such behaviour and these norms are important in all societies, although exactly the same rules do not necessarily apply to them all. Sunbathing naked in Berlin's Tiergarten may be acceptable and common while absolutely forbidden in London's Hyde Park. In most societies, excreting and urinating is unacceptable in public. There are conventions that draw a boundary between the private and the public, and indicate what behaviour is or is not acceptable in the public. In such cases, it is not only accepted by social norms that they are private, but we are not expected to expose them in public – at least not in the public space. This is built into social norms and institutions and is often associated with shame and taboos. Certain behaviour is shameful in public.

In his book *Public Goods and Private Goods*, Raymond Geuss discusses unwanted intrusion in public space and the case of Diogenes of Sinope (the Cynic).<sup>48</sup> Diogenes was notorious in Athens for challenging social norms, especially social norms protecting people from unwanted intrusion in public— for instance, when he masturbated at the busy marketplace. Not surprisingly Athenians strongly objected to his behaviour.

Geuss speculates about the reasons for objecting to Diogenes' behaviour and refers to what he calls the principle of "civil inattention".<sup>49</sup> The public space is one where anyone can enter and do their business without having anyone calling for special attention. We are not supposed to force ourselves into others' attention in such a way that obstructs people from doing their business; this is felt to be an intrusion in public. Furthermore, Diogenes' actions were looked upon as unclean and therefore wrong. As Geuss points out, there is a correlation between disgust and shame; we are ashamed (or should be) when we do things that disgust other people. Diogenes, however, was shameless in his disregard for social norms about public behaviour. His behaviour is a violation of the understanding of what belongs to the private and what belongs to the public, according to Geuss, although Athenians did not have such concepts at that time.<sup>50</sup>

There are many interesting questions that arise from the case of Diogenes. Diogenes makes a point of upsetting and challenging social norms that divide between the public and the private space. Social norms have many different roots and there might be good reasons for challenging them. Some social norms represent deep-rooted social prejudices against individuals or groups. There have been societies that have restricted public presence of disfigured or disabled people on the grounds that their appearances disturb others. Such

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<sup>48</sup> Geuss (2001).

<sup>49</sup> Geuss (2001) p. 13.

<sup>50</sup> Geuss (2001) p. 31.

requirements represent prejudices towards these individuals and groups who unwillingly draw attention to themselves. In such cases what is displayed represents a side to the society that some people or groups would like to keep hidden. Begging in the streets might be a sign of poverty affluent people would like not to be reminded of when they go out doing their business in public. When social norms are rooted in unjust social structure or prejudices it might be essential to challenge such norms and draw attention to these facts. Other examples such as child abuse or sexual abuse of one's spouse are similar; these are things that are hidden away and others often want to keep them that way.

How does this way of distinguishing between the private and the public relate to privacy? Someone who is not allowed to be in public but is required to hide away can hardly be said to enjoy privacy.. A disfigured person who is not allowed to show her face in public is not allowed to show her identity. She is non-existent in public and forced to be in private. This robs her of privacy in relation to this fact.

This discussion relates to contemporary issues of what exposure is tolerated in public space – for instance, of pornography and homosexuality. Pornography is an explicit portrayal of sexual matters. Some people have strong preferences for such matters; others disapprove of it very much or find it wrong. Although pornography is not banned by the state, we still may want to keep it out of public view. Those who find pornography morally wrong have an interest in not having pornographic pictures exposed in the streets or in the mainstream media. Having it in the open would lead to tension and possibly public collision. Therefore many have argued that pornography should be tolerated with restricted exposure. In this way pornography may be enjoyed secretly.

Some people also think homosexual preferences should be hidden in the private. However, homosexuality is an important part of personal and social identity, something that defines the individual and should therefore not be simply tolerated but accepted. Unlike preferences towards pornography, toleration of homosexuality is directed to people as such. It is our right not to be discriminated against because of the way we are. Requiring homosexuals not to show their identity in public is making it secret but not allowing them to enjoy privacy.

Therefore exposure in the public might serve as an important means to change perceptions and abolish prejudices. One way of making something acceptable in society and uproot shame that might be associated with it is precisely to expose it or display it in public. Gay Pride is an example of how homosexual culture is displayed and praised in public for everyone to see. As I will discuss below this causes some tension for liberals like Nagel who argues that less exposure is better because it diminishes the possibility of public conflicts.

Diogenes' case is similar to pornography. He is performing an action that people find disgusting or disturbing in many societies, not because it should not be done at all, but because it belongs in private, and should be done in secret. The same is true of many other bodily functions. We might therefore react similarly to how the ancient Athenians did – this activity cuts through societies and centuries. There may be good reasons for keeping the public free of certain kinds of behaviour. One reason might be because this behaviour disgusts other people. It is tricky to use disgust as a reason for restricting certain behaviour. There are many things people find disgusting, and some are for good reasons and others not.

Still another way of arguing against Diogenes' behaviour is to say that we should be able to control what we see. Restricting sexual activity in public is not directed at certain individuals or groups, nor does it have to do with unjust social structure. We simply object to

being exposed to certain kinds of actions. We might not want to see others in sexual intercourse or masturbating, not necessarily because we find it shameful or disgusting, but simply because we think this belongs to the private. We may say that we have such an interest and people should take notice of it. Given that we see Diogenes' actions as an intrusion upon others in the public sphere, one may ask if such an intrusion is a violation of others' privacy. I will discuss other cases of privacy within the public in chapters 3 and 4. For example, when we read on a bus it is inappropriate for others to try to read over our shoulder. One can say that we have created a space of privacy in public in such cases. It is even possible to argue that Diogenes is violating the privacy of others who are in the public space: he is forcing others to become a part of his private life or intimate actions – they are forced, in a way, into a private relationship with Diogenes. One reason we may find such a situation uncomfortable is that there are no social norms that apply to this situation in public. We may feel like we are eavesdropping against our will. Similarly we may feel uncomfortable if we witness a couple fighting in a public park. Not because of the content of the fight, but simply because we do not want to hear about such personal matters and are, as in the case of Diogenes, forced into a personal relationship with them.

We see from the above discussion the complexities of the intimate v. non-intimate distinction. Restricted access to certain behaviour is not necessarily granting people privacy. Requiring people to keep things private or secret can either be to preserve the privacy of others in public, such as in the case of Diogenes and pornography, or denying people of privacy, as in the case of homosexuals.

### *2.3.2 The distinctions are intertwined*

Diogenes is a nuisance, but is he violating someone's rights? He is not harming anyone and perhaps there is no reason to prevent him from exposure. Liberals have long been concerned about basing liberty restrictions on disgust or decency, and requiring people to keep things hidden seems not liberal in nature.<sup>51</sup> Nevertheless, this case causes some problems. Nagel is similarly concerned about public exposure, and he argues that conventions that protect people from too much exposure are important for a tolerant society. This is because, Nagel argues, there will always be people who find some behaviour disgusting. According to Nagel, social rules and conventions, which give people opportunity to keep things to themselves, are important to secure diversity by keeping disruptive material out of the public arena, thus avoiding unnecessary conflicts by "protecting private life from the crippling effects of the external gaze".<sup>52</sup> Too much exposure in the public gives people reasons for voicing their outrage and then the fight for control of the public starts.<sup>53</sup> Therefore, according to Nagel, it is better to have social norms that prevent people from exposing themselves or from taking part in certain kinds of behaviour in public. Here he is referring to the distinction between civil society and non-interference and linking it to intimacy and non-intimacy.

Nagel states, for instance, that "the more crowded the public arena gets the more people want to control it," which leads to both less personal control and less tolerance.<sup>54</sup> This means further that things that are exposed become other people's business: we risk that private things become a matter of the public and hence become subject to regulation and state interference. Nagel argues, therefore, that less exposure of the private in public leads to less interference of

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<sup>51</sup> Feinberg (1973).

<sup>52</sup> Nagel (1998) p. 17.

<sup>53</sup> Rössler has a discussion of this point and political correctness. Rössler (2001) p. 179-184.

<sup>54</sup> Nagel (1998) p. 9.

the state into private matters. And in the spirit of the neutral state he argues that we should keep private matters to the private space rather than exposing them in public.<sup>55</sup> Not everything can be tolerated in public and therefore we need the boundaries, between the spheres, to protect the public from too much exposure. Preserving the boundary between the private and the public with social conventions is important to protect pluralism and a tolerant society. The reason for restricting freedom based on decency in the public is therefore to minimize conflict.

Hence we see there is a difference between tolerance of the state and tolerance in the social sphere of interaction. Scanlon discusses this difference in his paper “The Difficulty of Tolerance” and separates what he calls formal politics of state laws and regulations and informal politics of social life.<sup>56</sup> According to him, a tolerant society is not only democratic in its laws and institutions but also in the informal politics where tolerance is importantly a matter of personal attitude. He argues in a similar fashion as Nagel that we all have an interest in how the informal social space develops. He points out, for instance, that we might not care if other people swim in the nude, but we might not want our society to evolve in such a way that swimming in the nude in public becomes a norm, making the alternative next to impossible. The same might be true of religion. We might not care if others attend to their religious practices, but might ourselves not want religion to become a central part in all public discourse.<sup>57</sup> Thus we all have the same right in defining and shaping the social space and it matters very much how it develops. We might want to remove religious symbols from the social space to have more neutrality. But in making the space more irreligious, we are replacing one value for the other but not making it more neutral. The attitude of tolerance in informal politics is about mutual respect that is deeper than apparent conflicts, whereas

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<sup>55</sup> Nagel (1998) p. 14.

<sup>56</sup> Scanlon (2003) p.190.

<sup>57</sup> Scanlon (2003) p. 191.



intolerance involves denial of full membership of the other. But it matters where the conflicts take place. Exposure in the public space makes it a public issue in the sense that people want to control it or regulate the behaviour. And Scanlon argues that the tolerant view might even need to accept the voices of the intolerant because intolerant attitudes in the public often call for reaction.

We see from this some of the problems Nagel and the liberal theory face in regards to exposing the private in public. According to liberal theory, people are free to conduct their lives according to their own values, free from governmental intrusion. However, the society or the state is allowed to prevent behaviours of certain kinds in public space if it might disgust some people even though the exposure does not violate any rights. This is against the general liberal principle that people should be free to do what they want unless they harm other people or violate their rights. However, Nagel argues, it is acceptable to prevent such actions because they might cause unnecessary conflicts, which might further lead to more regulations on behalf of the state and restrictions of liberty. Hence issues of intimacy and private space are intertwined with issues of decisional privacy.

#### *2.4 The importance of social norms*

We have seen in previous discussion how complex the relation between the private and privacy is. Furthermore we have seen how the distinction, especially the one between the intimate and non-intimate, is very much related to social structure and social norms. What we are able to expose in public or are required to keep private depends very much on social conventions. In this thesis I argue that privacy is a concept related to social structure. It is therefore interesting that Nagel, for instance, acknowledges in his discussion on the public-

private distinction how privacy is protected by social norms. I will discuss his arguments below.

According to Nagel, social norms protecting the boundaries between the public and the private have been deteriorating in the past decades, with bad consequences for liberal values. The social norms protecting the private space are both necessary to allow people to keep things out of the public, and also to protect privacy in the private space. He wants especially to restore the ‘convention of reticence’ and argues that it served an important role against the culture of forced exposure that characterizes more and more modern western societies.<sup>58</sup> According to him, reticence and non-acknowledgment refers to the importance of being able to hold back and not being required to express our thoughts in full honesty in public. These norms are important, according to Nagel, for two reasons. First, they protect our inner life from public exposure.<sup>59</sup> We are different individuals with different desires and thoughts, and it is important for human flourishing to be able to conceal them or control whether we share these thoughts and desires and with whom. Social conventions like reticence protect privacy, and promote an individual’s control of what he or she expresses to others. Second, various social conventions, such as social chat and courtesy rules, serve the important functions of protecting us from unwilling conflict in public.

One can question whether the convention of reticence is as important as Nagel claims. There is almost a nostalgic tone in his writing; he seems to long for the social norms of the past. Surely social norms and technology have been changing, making personal exposure more common than before. We can, however, dispute whether the convention of reticence in the past served all that well. Then, people were required to keep things private that were important

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<sup>58</sup> Nagel (1998) p. 4.

<sup>59</sup> Nagel (1998) p. 10.

for their representation in the public, and such requirements were based on norms that favoured certain groups and values. Such social conventions are not under individual control. During periods of shifting conventions, people may experience loss of privacy because of changes in social conventions in regards to the older norms. If privacy is rooted in the social norms, this is only a loss relative to the older norms. Nagel argues that we should be allowed to keep things private, and that for protecting privacy we need also to have social norms of good manners and the principle of reticence. The state can only enforce some of these privacy concerns within the legal framework. Still, there are important privacy issues at stake for members of the society.

There are, however, interesting aspects to Nagel's discussion of social conventions. According to Nagel the convention of reticence serves to protect the boundaries between the public and the private because it helps keep things or activities hidden from the public sphere. However his description of this convention shows that he is not referring to the ability to keep something hidden or as a secret. He says: "If something is not acknowledged, then even though it is universally known, it can be left out of consideration in the collective social process, though it may play an important role separately in the private deliberations of the individual participants. Without such traffic control, any encounter might turn into a collision."<sup>60</sup> Here Nagel argues that we need to be able to go about in public and meet people without unwelcome conflicts.

This shows that the convention of reticence refers to relations between people: how people indicate that they know without stating what they know explicitly, and how people can refer to mutual understanding in this respect. Nagel points out that the conventions that govern

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<sup>60</sup> Nagel (1998) p. 12.

most important forms of reticence are “generally known”.<sup>61</sup> Although Nagel refers here to the private or restricted space he seems to be referring as much to the distinction between intimacy and non-intimacy; how there are certain things we are allowed to keep for ourselves. The social norms that he refers to are in fact relational, depending on complex structure. This is especially interesting when Nagel refers to private space as space that is restricted or hidden. The nature of what is secret or hidden is that it is *not* known by others, but we see how the convention of reticence is about what is known or acknowledged between people. Holding back in a conversation between people does not require a hidden space nor does it refer to secrecy. Rather the convention of reticence is about what we share or not share, how we express things, and whether we have mutual understanding on these matters. This point will be discussed further in the next chapter and in relation to other social norms.

What we can conclude from this is that contrary to Nagel’s argument a public-private distinction which is about space or collective interests does not have the right tools to capture the important issues of the convention of reticence. Thinking about the convention of reticence in relation to private space turns our attention in a wrong direction; we can more fruitfully think of the issue in terms of what is shared or unshared and in terms of the social norms that underwrite sharing conventions.

Although Nagel associated privacy with the private sphere or space, the merit of his analysis is that he acknowledges the importance of social norms and social practices for protecting privacy. Nagel’s discussion, however, reveals how dependent we are on social norms to protect our privacy – and how powerless individuals are against social norms and conventions. Furthermore his discussion reveals how important social norms are for protecting

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<sup>61</sup> Nagel (1998) p. 6.

individual privacy in everyday interaction. These informal social interactions are guided by social conventions and courtesy rules, and societies differ in these respects. As Nagel's examination shows, some of the intrusions into people's privacy do not come from the government or state, but from what he regards as breaking down of social conventions. As I have already discussed, the different public-private distinctions are intertwined. The social conventions drawing the distinction between public and private space may also support the distinction between state and civil society.

Furthermore the discussion shows how the boundary between the public and the private is never drawn once and for all: the boundaries are dynamic and they are constantly being negotiated. We need to take into account the fluidity of modern diverse societies where social norms are ever-changing. Such norms and conventions are not easily controlled. We cannot overlook the changes to the public sphere with new information technology, making public exposure more intense and everlasting. This change does not necessarily call for restoring old conventions, but rather requires new norms and conventions. The fluidity of social conventions also causes problems for individual control of the social boundaries.

### *2.5 Different languages – different cultures*

We have seen how the public-private distinction depends on social norms and social structure; privacy changes with generations and is different between different societies.

The fact that the literature on privacy is relatively new points to the social changes generating the interest. Profound social changes of the last century have disrupted social norms that were in place protecting privacy and traditional boundaries between the public and the private. Those changes are due to women's liberation, feminism, the rise of corporate interest in individual information and behaviour, and enormous technological development.

The result is changes in the division between private and public and in the social understanding of what is private and what is public. When we examine other cultures or languages we have another picture, and the conceptual relations between privacy and the private are not always present. This is at least the case in the Icelandic language.

The fact that privacy is embedded in the social structure raises the question whether privacy is a culturally-relative concept. This difference between societies will be touched upon again in chapter 4 where I discuss personal information in relation to genetic information and databases. Societies differ also in having different limits to their privacy and personal space. This cultural relativism of privacy has been recognized and discussed somewhat in the literature.

In his book *Privacy: Studies in Social and Cultural History*, Barrington Moore argues that recognition of privacy can be found in different societies.<sup>62</sup> His cases are as diverse as Ancient Greece, Ancient China and the Old Testament. In his study it seems that people in different cultures want to keep things away from others and these cultures have developed norms to protect what most often is seen as privacy. This study shows that many social conventions in each culture have ways to protect the private lives of individuals and these social conventions are marked by shame and taboos.

When comparing concepts in such a way between cultures and between historical times we need however to be cautious. Although the word “privacy” is not entirely new it is used in a different way now than before, and the cultures in Moore’s study did not use the same concepts for it as we do today, and in some cases no concepts at all for what we now mean by privacy. Moore is therefore reading privacy, not recognized at the time, into old texts and

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<sup>62</sup> Moore (1984).

stories, interpreting them as cases of privacy. With new concepts come new ways of thinking about social structure and in fact change our understanding of society and human interest in profound ways.

### *2.6.1 Privacy in Icelandic<sup>63</sup>*

From the beginning there has been criticism of the meaning of privacy in English and controversy over its definition.<sup>64</sup> If it is unclear in English we can legitimately ask how the English term “privacy” translates into other languages.<sup>65</sup> Is “privacy” broader or narrower in other languages? In my discussion I will especially focus on Icelandic culture and language. Anyone writing about privacy in Icelandic has to tackle conceptual problems since the Icelandic term has a different origin from ‘privacy’. Implementing European directives necessitates some conceptual work and adoption of language and culture. My approach is descriptive; I simply want to present the problems and the difficulties.

If we look at the meaning of ‘privacy’ in English we see some distinct characteristics. We have seen how the term ‘privacy’ is importantly linked with private affairs and the private sphere. Private is what is opposed to public and the public sphere; what is private we keep away from the public eye.<sup>66</sup> As the term has been interpreted in many legal cases, privacy is an individual’s control over his or her affairs. By control of privacy the individual has at least the

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<sup>63</sup> This section is based on Nordal (2007b).

<sup>64</sup> This will be discussed further in chapter 2.

<sup>65</sup> Although if it were clear in English, we could still legitimately ask how “privacy” translates into other languages.

<sup>66</sup> Patricia Boling traces several different meanings of ‘private’ and distinguishes between four different meanings or senses of privacy rooted in the private: 1) the meaning of private which has to do with lacking something or being deprived of something. For instance people who were lacking social status are private in this sense. 2) the meaning has to do with protection or confidentiality, something that justifies limited access of others. 3) the meaning has to do with one’s ability to exclude unwanted others. 4) the meaning suggests possession or control in the sense of private property. Taken together Boling argues that there is a tension between two separate meanings of privacy, rooted in ‘private’, namely between what needs to be protected or controlled and what is deprived or privative, what lacks public support or recognition. Boling (1996) chapter two.

control to decide when or whether to make private matters public. This is so in spite of the fact that the distinction between the public and the private is always to some extent grounded in social conventions.

In Icelandic ‘friðhelgi’ has been used to represent ‘privacy’ in English. This term can be found in old Icelandic and its meaning comes from two separate words ‘friður’ meaning ‘peace’ and ‘helgi’ meaning ‘sacred’ or ‘holy’. The concept ‘friðhelgi’ means therefore something we have in peace or is sacred to us (often space). The term ‘helgi’ is often used with other terms such as ‘landhelgi’ or ‘lofthelgi’ meaning the national territorial waters and airspace. If something has ‘friðhelgi’ our access to it is restricted in meaningful ways. Icelandic members of parliament have ‘friðhelgi’ for instance and that means that an MP cannot be prosecuted for anything he or she says in the parliament; in medieval times churches were ‘friðhelgar’ for individuals within the church walls, which meant that individuals could not be apprehended or killed there; they had sanctuary or were granted immunity. And as in many countries the ‘friðhelgi’ of the home is well recognized and has been for a long time.

From these examples we can see that ‘friðhelgi’ has a fairly clear meaning. It is a place that has restricted access or is our sanctuary. The first difference we see between the English and Icelandic term is that ‘friðhelgi’ has no reference to the private sphere, and from the examples above we see that it is used with public as well as private phenomena. Unlike privacy in public, which sounds like a contradiction in English, friðhelgi within the public poses no conceptual difficulties in Icelandic.<sup>67</sup> Another different feature is the strong social reference and weak reference to individual control within the Icelandic tradition. For ‘friðhelgi’ to be respected there must be a general consensus within the society. Third, ‘friðhelgi’ is

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<sup>67</sup> Recently many have argued that it is important to recognize privacy in public. See Nissenbaum (1998) and Nissenbaum (2010).



traditionally not used without specifying what it refers to. This is clear in ‘friðhelgi heimilisins’ or the privacy of the home. This keeps the clarity of the concept and the connotation intact.

An exception to this tradition was made recently when the Icelandic Constitution was revised to meet some standards of *The European Declaration of Human Rights*. To capture the meaning of the English term ‘privacy’ more precisely the concept ‘friðhelgi einkalífsins’ was implemented.<sup>68</sup> In Icelandic ‘einkalíf’ means the private or private affairs and ‘friðhelgi einkalífsins’ is therefore coming close to the meaning of ‘privacy’ and reference to the privacy sphere. And of course with this adoption comes a broader concept than before. This change is only recent and very few cases have been tried referring to this broad notion. It remains to be seen how this new concept will develop and whether it will take on as many shapes as the equivalent term in U.S. courts.

More recently still another term, ‘persónuvernd’ which literally means protection of persons, has been used in Icelandic for privacy interests and has mainly been used for various data protection and informational privacy. The concept ‘persónuvernd’ does not appeal to individual control but rather places the emphasis of this interest in the hands of others, the importance of protecting persons from intrusion or misuse. And interestingly the emphasis is on protecting persons but not data.

Anita Allen argues that in spite of the number of formal US privacy laws – there are possibly more of them in the US than anywhere else in the world – privacy laws are still lacking in many areas; for instance, in relation to the internet, genetic information and data protection.<sup>69</sup> In contrast most EU countries, which have only slowly followed the US tradition, have implemented *The Directive of the European Parliament and the Council of Europe on*

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<sup>68</sup> This happened in 1995.

<sup>69</sup> Allen (2004).

*the Protection of Individuals with Regard to the Processing of Personal Data and on the Free Movement of Such Data.*<sup>70</sup> These directives set limits to using personal information for instance in genetic research and for any use of genetic information. In Iceland for instance the Data Protection Authority – called ‘Persónuvernd’ in Icelandic – enforces the law.

It is interesting to reflect on the differences between European and American interests in privacy. The American interest in privacy seems to be more focused on individual control and entitlement: the right to make decisions about individual affairs and control personal information. There is a reluctance to place the protection of privacy in the hands of social institutions rather than in individual hands, or to regulate business and public institutions in this regard. The European attitude on the other hand seems more focused on the reaction to information technology and the importance of building institutions that can protect individuals in this new environment. As I argue later, building trustworthy institutions might be the only possible way of protecting the interest of privacy in the technology age of cyberspace and genetic databases.

The scholarly discussion of privacy has been dominated by American culture and juristic language. At the outset it may look like Americans are more conscious about privacy than Europeans.<sup>71</sup> A closer look may, however, show the opposite to be true. Nicola Lacey points out that privacy has to be read between the lines in English law and from the few examples I have discussed from Iceland we see that ‘friðhelgi’ has been a legal term in Iceland since medieval times.<sup>72</sup>

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<sup>70</sup> Council Directive 95/46/EC of 24 October 1995 on the protection of individuals with regard to the processing of personal data and on the free movement of such data, OJ 1995 No. L 281, 23 November 1995.

<sup>71</sup> Allen (2004) p. 28.

<sup>72</sup> Lacey (2004) p. 45.

Therefore it is too hasty to argue that there is less concern for privacy for instance in Iceland. These cultural differences merit closer scrutiny and examination. The point of drawing attention to them here is to address the cultural differences in relation to privacy. Not only is there a difference between cultures in what is regarded as private and merits privacy protection, but also is there a difference in the way the concept is structured and used in different languages. As we saw the original meaning of the Icelandic concept of privacy does not have a reference to the private.

## *2.6 Conclusions*

The three different public-private distinctions discussed in this chapter – the distinction of non-interference, between private and public space, and intimacy and non-intimacy – show that none of them individually map into privacy, nor do they collectively do so. All of them show some aspect of privacy but miss how privacy has to do with relations between the public and the private. We saw how privacy has been related to the sphere of non-interference as decisional privacy. However, the features of decisional privacy show that this distinction is really about freedom and not privacy. Therefore privacy has been more related to the other two distinctions: the private space and intimacy. Privacy is often associated with the space of restricted access, where we can hide from exposure. Nevertheless being required to hide in the private does not secure privacy and does in fact prevent people from enjoying privacy.

We have also seen how privacy is not only related to the private space but also to the public. Two separate issues have been discussed in this chapter in relation to privacy in public. First, that we can enjoy privacy in public space, such as when we have private conversations in a public park and others are not supposed to sit too close and eavesdrop. Second, privacy can be violated by exposure in public, for instance in the case of Diogenes. There is an interest

in not only controlling, to an extent, what we are exposed to in the public, but also in not being forced into a “personal relationship” with someone who exposes his personal activities. We usually want to hide intimate things in the private, but wanting to hide and being required to hide are two different things when it comes to privacy. Requiring people to conceal their sexual identity in public means that they have to keep it secret; it is hidden from the public. Privacy, however, depends on the relations we have with others; it must be granted by others.

This shows how different public-private distinctions are importantly intertwined. Most often the distinction between public-private space is conflated with the one dealing with intimacy and non-intimacy: we prefer to, or are required to, do intimate things in private space hidden away from others. It is however important to keep them apart.

In the last two sections of this chapter I discussed how social norms and conventions play a role in protecting privacy and the distinction between the public and the private. A careful reading of Nagel shows how relational the concept of privacy is and how individuals are in many respects dependent on others in protecting their privacy. This social aspect of privacy is reflected in the concept of privacy in some other languages. Although privacy is conceptually related to the private this is not the case in all other languages as my examination of Icelandic language showed. There we both saw that the Icelandic term for privacy, *fríðhelgi*, can refer to the public sphere as well as the private and that it depends very much on the social norms. This will be the basis of my criticism of the two models of privacy, discussed in the next chapter, which represent the traditional perception of privacy in the literature.

### Chapter 3: Traditional Perceptions of Privacy

In the vast literature on privacy, where it is common to argue that the concept of privacy is hopelessly broad and elusive, we find numerous attempts to sort out privacy interests, propose definitions of privacy, and examine reasons why privacy is important. Similarly there are available almost as many evaluations and critiques of these definitions.<sup>73</sup> In this chapter some of the main themes of the privacy literature will be introduced, discussed, and examined, with a special focus on privacy definitions. This is not meant to be a full review of the literature by any means; rather an attempt to identify the main limitations of different privacy understandings with the aim of setting the stage for an alternative view.

Even though the first issue, privacy definitions, will take up a good part of this chapter, I will only give a very broad outline of the subject. There I will follow a trend in the literature of distinguishing between two groups of privacy definitions: privacy defined in relation to limited or restricted access, and privacy defined as constituting individual control.<sup>74</sup> The former, *the separation model*, explains privacy as being separated from others and as “antithetical to publicity”.<sup>75</sup> This model describes privacy in a neutral way. The latter, *the control model*, explains privacy as having control of particular situations, that is, controlling if, when, how and with whom we share our space or personal information. This view defends privacy as a value and defines the extent to which it should be protected. Within the literature we find both many variations of each model as well as attempts to combine the two.<sup>76</sup> These two models should therefore not be regarded as contrasting models. Nevertheless both of them fail either because they are too broad or they overlook important features of privacy. As we

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<sup>73</sup> See recent reviews in Solove (2008), Anderson (2008), Matheson (2008), Nissenbaum (2010).

<sup>74</sup> Inness (1992) p.5-6, Powers (1996) p. 372-375, Matthews (2008) p. 138-139, Nissenbaum (2010) p. 70.

<sup>75</sup> Inness (1992) p. 5.

<sup>76</sup> Matthews (2008).

will see both these models relate to the public-private distinction. The separation model is obviously about distinguishing between the public and private in relation to access and the control model is about control of certain areas of life that belong to the private sphere.

The second theme of this chapter is the value of privacy, an issue that cannot always be separated from definitions of privacy. There are several different arguments stating why privacy is important. Again we can say that two of them are most prominent in the literature: privacy to protect personal relations such as intimacy and friendship, and privacy to protect autonomy. These two accounts of privacy's value have somewhat different underpinnings: Views that argue that privacy protects intimacy and friendship relate more strongly to restricted access accounts of privacy, but the view that privacy protects autonomy relates more strongly to the control model of privacy. However, there are also versions of the control model that argue that privacy is valuable both to secure autonomy and intimacy. As we will see privacy plays an important role in friendship and intimacy, yet at the same time a necessary connection cannot be established. The same is true of autonomy; privacy plays a role for autonomy but a necessary connection between the two cannot be established.

My main criticism in this chapter relates to the social aspect of privacy and how the traditional understanding of privacy tends to overlook the role of social norms in both providing individuals with privacy and protecting privacy in every society. Throughout the chapter I will voice this criticism and suggest another way of thinking about privacy. In the last part of this chapter I will sketch an outline of an alternative account of privacy: privacy as a social concept. This account of privacy acknowledges how privacy is deeply embedded in social norms and practices. It does not depend on the public-private distinction, or a relation

between privacy and the private, but rather highlights the relations aspect of privacy and how it is defined within different relationships and institutions.

### *3.1 Privacy as restricted access – the separation model*<sup>77</sup>

As discussed in the preceding chapter privacy is often seen in relation to the private and in contrast to the public.<sup>78</sup> According to this view privacy relates to a state of restricted access to the individual; there have been many attempts to define privacy in relation to inaccessibility or separation. Anita Allen argues that “personal privacy is a condition of inaccessibility of the person, his or her mental states, or information about the person to the senses or surveillance devices of others.”<sup>79</sup> Similarly Ruth Gavison states that “in its most suggestive sense, privacy is a limitation of others’ access to an individual.”<sup>80</sup> Consequently a person who is not accessible to others or is having privacy “is beyond the range of others’ five senses and any devices that can enhance, reveal, trace, or record human conduct, thought, belief, or emotions.”<sup>81</sup>

This definition coincides with a common understanding of privacy as being away from others and with our practices of restricting access – for instance to our homes, private space, access to personal data and having legal rules against eavesdropping and wiretapping.<sup>82</sup> Both Gavison and Allen argue for multidimensional privacy; it may contain restricted access to physical space, restricted access to personal information, and limited interference with personal decisions.<sup>83</sup>

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<sup>77</sup> The label “separation model” comes from Julia Inness. See Inness (1992).

<sup>78</sup> Boling (1996) examines this claim and finds it problematic.

<sup>79</sup> Allen (1988) p. 15.

<sup>80</sup> Gavison (1984) p. 350.

<sup>81</sup> Allen (1988) p. 15.

<sup>82</sup> Allen (1988) p. 12.

<sup>83</sup> Gavison (1984) p. 347. Allen argues for four dimensions of privacy. Allen (1997)

This account of privacy has several features. First, the proponents of the separation model start their inquiry into privacy in a descriptive manner and explain it in a neutral way as restricted access, which means that whether privacy is positive or negative depends on the circumstances. Accordingly people can be criticised for either choosing privacy or for not choosing it. A person who has withdrawn from others might be doing so to benefit her life or to escape obligations. Gavison argues that the neutral understanding of privacy serves the important function of identifying when loss of privacy does occur, a loss which is not dependent on the wishes or claims of the individual, but simply on the fact that the person is accessible to others.<sup>84</sup>

Second, this definition is closely linked to our understanding of the difference between privacy and publicity. Privacy understood as limited access aims at defining the boundaries between the private and the public and relies therefore on the public-private distinction, discussed in the last chapter. This matches with our ordinary understanding of privacy in the English language where privacy relates to the private sphere. However the division between something that is hidden from the public eye or public space and that which is open or accessible is not culturally dependent – all cultures have spheres where something is hidden.<sup>85</sup>

Third, according to privacy as restricted access privacy comes in degrees. This is explained by Ruth Gavison where she refers to perfect privacy, as a place to start from: “[I]n perfect privacy no one has any information about X, no one pays any attention to X, and no one has physical access to X.”<sup>86</sup> Gavison is quick to add that perfect privacy is impossible in any society just as is total loss of privacy. Loss of privacy occurs when we are in relation to

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<sup>84</sup> Gavison (1984). One reason Allen argues for privacy as a neutral concept is to be able to argue for privacy for women. See Allen (1988) chapter 2 and Allen (1990).

<sup>85</sup> Margalit (1996) p. 202.

<sup>86</sup> Gavison (1984) p. 350-351.



others: it “occurs as others obtain information about an individual, pay attention to him, or gain access to him.”<sup>87</sup> We are always, from the day we are born, already in relation with other people and interacting with them. We often refer, for instance, to our privacy as a sphere we share with our closest friends or relatives. What we have here is a degree of privacy not perfect privacy where we are not observed or accessed by anyone.

From this outline of privacy as restricted access we see that the concept is both neutral and fairly broad since it can be of positive or negative value but forms a basis for more value-laden understandings. According to both Gavison and Allen the neutral concept of privacy is “a parent concept” for other forms of privacy such as seclusion, secrecy, confidentiality, anonymity, and solitude.<sup>88</sup> As will be discussed below, this definition of privacy includes therefore a shipwrecked person finding herself alone on an island since she is not accessible to others and thus is in total solitude or isolation.<sup>89</sup>

The separation model has been criticised for various reasons. Julia Inness, for instance, argues against privacy as value neutral, where losing or gaining privacy has no moral meaning.<sup>90</sup> She takes an example of someone who is separated from others against her will. According to the separation model a person locked up in a room and not accessible to others is having privacy in spite of her wanting to get out and wanting to lose rather than gain privacy.<sup>91</sup> This certainly sounds strange to anyone who refers to the value of privacy we express in common language as something we “enjoy”.

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<sup>87</sup> Gavison (1984) p. 351.

<sup>88</sup> Allen (1988) p. 3, Gavison (1984) p. 351.

<sup>89</sup> Although it is a fairly broad understanding of privacy it is meant to exclude issues that have sometimes been defined as privacy issues such as intrusion with smell and unwanted phone calls.

<sup>90</sup> Inness (1992) chapter 4

<sup>91</sup> Inness (1992) p. 44.

Inness also criticises the separation model for being individualistic in the sense that privacy is lost “as soon as one individual encounters another”.<sup>92</sup> According to Inness this understanding of privacy goes against our common understanding of privacy as something we can share with others, such as when we invite close friends to our home or enjoy privacy with our family. According to the separation model privacy is lessened when we are with others. However, as described earlier, Gavison acknowledges that perfect privacy is an impossible human condition and argues that individuals must always be in a state of balance between privacy and interaction.<sup>93</sup> Furthermore, according to Gavison, privacy is not an all or nothing concept but rather comes in degrees; therefore, it allows for restricted access with more than one person, and thus entails a degree of shared privacy.

### *3.1.1 Privacy and social norms*

There is still another criticism posed by Inness and is directed at cases we intuitively would regard as a violation of privacy, but would only be a threat to privacy according to the separation model. Inness takes an example of someone reacting to a peeping tom by hiding under the bed, and she argues that according to the separation model this is not a privacy violation because the person has managed to keep access restricted.<sup>94</sup> According to the separation model she might have experienced a privacy threat but no real privacy violation has taken place.

This example merits some further examination and as I will discuss later it is not clear that it can adequately be explained by the control model either. We have many ways to withdraw from others’ attention to restrict access to ourselves. Some examples are to build a

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<sup>92</sup> Inness (1992) p. 43-44.

<sup>93</sup> Gavison (1984) p. 359.

<sup>94</sup> Inness (1992) p. 46.

fence between ourselves and our neighbours, or get curtains in a dense subdivision, or hide under the bed when we have a peeping tom at our window. In all these cases we might say that there was a possibility of loss of privacy before action was taken to build a fence, get curtains or hide under the bed, but with the action taken the person has privacy of restricted access. However these examples are different in an important way as it cannot be correct to say that the person hiding under the bed is only experiencing a threat of privacy loss but no violation has taken place. So what would be the difference?

Building a fence or putting up curtains are socially accepted ways of gaining or protecting privacy, and are clear indications that you want to be private in your house or around it. Furthermore, such actions are accepted by others as a sign of privacy and hence should be respected by them. Respecting them means that others should not drill holes in the fence to peep through, or peep through holes that happen to be there, nor should they try to see through the curtains. Similarly we are required to respect private homes: not to peep through windows; not to force people to move under their bed or into other rooms to escape our eyes. The concept of social norms is the key here – not what we can or happen to see, but what we are required to do. With privacy norms come certain requirements on the other: how we are supposed to respect the privacy of people and what actions people are allowed to take to protect their privacy. We should not be forced to hide under our bed to have privacy within our homes. In the absence of such social norms we are not able to distinguish between hiding under our bed or putting up curtains for our windows.

One can even argue that the concept of a peeping tom is not understandable without the backdrop of such social norms. A nice example from Margalit portrays this where he recalls a conversation with an elderly lady in Hampstead Heath on a sunny day where Londoners were

sunbathing. The old lady got angry at the fact that one of the women was wearing her underwear and thought it was indecent to strip like that. When Margalit asked about a woman in a bikini the old lady said that was different: “underwear is private”.<sup>95</sup> From the outside there is no difference between the two outfits; they cover the same body parts from public exposure. Still these outfits were interpreted differently by this elderly woman.

The separation model carries some important understandings of privacy as being away from others. It coincides with the traditional understanding of privacy as originating from ‘the private sphere’ suggesting conceptual relations between ‘the private’ and ‘privacy’ and was discussed in the preceding chapter especially with respect to providing space. I agree, however, with Inness and other critics that it is too broadly defined, but my concerns relate to the social aspect of privacy - privacy must always be defined in relation to others or social practices. Even though Gavison and Allen start their inquiry into privacy with a broad notion of privacy, they develop from there a narrower concept where they identify in which cases privacy is valuable and merits legal protection.

The advantage of starting with a broader concept is that it allows Allen and Gavison to identify situations where privacy may have negative value. Nevertheless when isolation and secrecy are defined under the privacy heading it broadens the concept too much. Privacy may in some cases look like isolation, a separation from others; there are however important differences. If isolation includes a person shipwrecked alone on an island, like Robinson Crusoe, who is obviously away from others, it would be strange to say that he is experiencing privacy. Crusoe’s situation is best described as isolation because no one knows of him on the island and he cannot reach out to anyone. If someone comes unexpectedly to the island the

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<sup>95</sup> Margalit (1996) p. 201-202.

person would not be invading Crusoe's privacy but she would be ending his isolation. If that same person would stay on and share the island with Crusoe they might possibly develop some rules of interaction, rules that might be similar to norms granting each other privacy. As we saw when discussing the example of the peeping tom, this is not only about restricted access but rules of what it is appropriate to do.

The crucial part of Crusoe's isolation is not that he has no control of the situation or that the situation is forced but not chosen, as Inness argues, but that in his situation there is no reference to others or shared social norms.<sup>96</sup> There is nothing that could count as his privacy in the absence of possible relations with others. It has no meaning to talk about privacy unless we have some social norms to refer to. Individuals like Crusoe do not unilaterally decide the norms; the norms are formed between people and we usually have to accept the norms that are already in place in each society. We have norms around setting up curtains. These norms state that what lies behind the curtain is private and it is inappropriate to look through them. Also there are norms to wearing bikinis rather than our underwear in public. Privacy, even in the case where the person is alone, cannot be the same as isolation because privacy is always defined with reference to others and depends on respect from others. Hence there is an important difference between being alone and being in seclusion or isolated.

Privacy as restricted access is not only about being away from others, but also about the norms at play. I have argued that privacy is always in relation to others but not in isolation. As such we can define privacy within the public sphere, as a sanctuary that is protected by social norms and dependent on people respecting these social rules, rather than as a distinct sphere outside the public.<sup>97</sup> Even in public places we have social norms protecting private things or

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<sup>96</sup> Inness (1992) p. 44.

<sup>97</sup> See also discussion of Icelandic language in the final chapter.

activities, norms that we are required to respect. For instance, we should not read over the shoulder of the person sitting in front of us on the bus, nor should we eavesdrop on the couple whispering on the bench in the public park. Similarly in the open park on a sunny day we may put out a blanket to sit on. Thereby we have demarcated certain space that others are supposed to respect both by not sitting on the blanket without our permission or eavesdropping on our conversation.<sup>98</sup> Therefore private space can be granted within public settings. The private is defined within the public and is its subset where others define, through social norms, what can be private and grant the private sphere proper respect. Just as others are required to respect signs of privacy such as curtains and fences, we are not supposed to build too high a fence. Such an act may be interpreted as an indication of distrust.

If we see the private as a subset within the public, rather than a sphere outside the public, like a deserted island, it enables us to see how we sometimes have subsets within subsets. Prisons are often seen as paradigm places of totalitarian institutions where privacy of inmates is next to impossible. Within prisons where individuals may experience almost complete solitude it might be strange to talk about having privacy. Solitary confinement is not the same as having a room of one's own. In prisons the inmates are not granted the same social norms as they would enjoy in other parts of the society, at least in regards to privacy norms, and the situation is totally beyond control of the individual. Inmates in prisons cannot rely on social norms protecting privacy such as having the prison guards knocking before entering the cells or granting privacy in other ways. In this sense prisons are outside the society or beyond the sphere of social rules. At the same time we are appealing to a set of norms when we describe them as lacking privacy. Hence we can argue that they lack privacy against such background

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<sup>98</sup> An example from Ann Levey.

sets. Similarly we evaluate the possibility of privacy in societies other than our own against our own privacy norms. In a society where there is no habit of knocking before entering a room a lack of such a social norm would not be regarded as a lack of privacy. There would be no lack of privacy of not knocking either in prisons or elsewhere. Prison inmates do not share space with the guards on an equal basis. Furthermore there is a missing condition of trust between the prisoners and the guards, and therefore it is not possible to trust that the guards act according to privacy norms.

When defining privacy Gavison starts with what she labels as “perfect privacy” and argues that it is always already limited to a degree. It is correct that privacy comes in degrees but beginning with perfect privacy seems to me to be the wrong end to start from. In a state of “perfect privacy” a person is deprived of all human interaction, something no one would want to experience and might in fact be people’s worst nightmare. Although “perfect privacy” is an unrealistic start, this approach is highly influential for the literature on privacy, since many see it as Gavison does, as privacy as a space away from others. Referring to total isolation as ‘perfect’ sustains the sharp demarcation between the public and the private. A more realistic approach is to start with the fact that we are always sharing space and information with others and from there we can have degrees of privacy.

According to the above description the private should not be seen as being in stark opposition to the public; rather these two spheres are intertwined and dependent on each other. Also this interaction between the public and the private is importantly defined by social practices and norms. Since most of our activities in private and our private affairs involve other people, we are depending on them and trusting them in sharing our privacy. Thus privacy is importantly dependent on social norms and social fabric. These social practices may

have developed somewhat differently in different societies. In some societies there might be more awareness of privacy protection and the social norms better placed to respect the private. In other societies there might not be the social norms protecting privacy. Furthermore we see from the discussion that there is not a sharp distinction between the public and the private, but we should rather see it as intertwined where there are subsets within subsets.

The separation model presents too broad a notion of the concept. I have emphasised how privacy as restricted access does overlook social norms and structure. In addition to classical criticism of the separation model of privacy my main criticism is that it fails to separate various different cases of restricted access as privacy, such as hiding under the bed or putting up curtains. The question is if defining privacy as control fares any better.

### *3.2 Privacy as control of access and personal information. The control model*

The dominating definition of privacy in the literature is privacy as constituted by individual control.<sup>99</sup> Alan Westin defined privacy as “the claim of individuals, groups, or institutions to determine for themselves when, how, and to what extent information about them is communicated to others.”<sup>100</sup> According to Inness “privacy is the state of the agent having control over a realm of intimacy, which contains her decisions about intimate access to herself (including intimate informational access) and her decisions about her own intimate actions.”<sup>101</sup> Beate Rössler argues that any definition of privacy is incomplete without this feature of individual control; she says: “if a state of isolation, seclusion or secrecy is enforced and not freely chosen, in other words if the person in question has no control over it, then one would

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<sup>99</sup> Parent (1983b) p. 272. Inness (1992), Reiman (1976), Gross (1971), Rössler (2005), Kupfer (1987) Rachels (1975).

<sup>100</sup> Westin (1970) p. 7.

<sup>101</sup> Inness (1992) p. 56.



not describe it as “private”<sup>102</sup>.

From these we see that the scope of privacy under the control model can be broad and can refer to different dimensions of privacy such as physical and informational privacy.<sup>103</sup> Inness is interested in the relation between control and the intimate realm and therefore many of her examples focus on physical privacy. Nevertheless the most prevailing account of privacy in the literature is privacy as control of personal information.<sup>104</sup> I will discuss here the control model as a control of both space and information, but a deeper analysis of the informational aspect of privacy will be presented in the next chapter.

Inness argues that the control model gives a more realistic account of privacy than the separation model and can better meet its shortcomings. First, according to the control model the condition of privacy has to be chosen. A person locked up in a room against her will is not experiencing privacy but something else, which explains why prisoners lack privacy. According to Rössler in the quotation above, such a person would not even count as being in private.

Second, according to the control model it is easy to explain how privacy is shared with others. When we invite others into our private sphere or share with them our personal information, we are not losing privacy but exercising privacy, our control over our personal affairs. When we share our private affairs we have relinquished our privacy to a degree; the other person has gained access to some important things. It is the nature of marriage and family life that we share our personal life to a large degree. However the point is that we have done so willingly and thus our privacy has not been violated.

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<sup>102</sup> Rössler (2005) p. 7.

<sup>103</sup> It also refers to decisional privacy that I leave out.

<sup>104</sup> In most of the papers in Paul, Miller, and Paul (2000) privacy is understood as control of personal information.

Sharing privacy and control raises the question of what it means to have control and to what extent we have control of a particular situation. When we invite someone into our house we are exercising privacy according to the control model; whether our control stops there or continues depends on how the situation develops. Inness discusses two cases to show the difference between initiating a situation and regulating the situation as it develops.<sup>105</sup> In the case of a friend we invite to our home, it seems like we have not only initiated the situation but we also control it, and we have the reasonable expectation that we can ask them to leave. The situation is, as Inness says: “backed up by a complex web of social conventions and norms of friendship”.<sup>106</sup> The other case is of a salesperson who starts reading our personal correspondence on the table, after we voluntarily allow her to enter our house. In this case it would be odd to state that the person is entitled to read our personal mail since we controlled her entrance in the first place. According to Inness we had control of the situation at the beginning but our control and our privacy stopped at that point. Therefore, the friend case is a case of shared privacy where we are in control but not the one with the salesperson.

These two cases show how vulnerable our control can be in a given situation. Moreover they show, as Inness acknowledges, how our control must be supported by social norms and structure to have a force. When we share our private homes with friends, such a situation is structured by social standards or norms in ways that restrict the actions of our guests; for example, reading titles from the book shelf is accepted but not opening drawers or reading personal letters lying on the table. The control model portrays the individual as having control but we can in fact question to what degree we have control of any given situation, even in the case of our friends. In such a case our guests are complying with social rules and it is really up

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<sup>105</sup> Inness (1992) p. 48-49.

<sup>106</sup> Inness (1992) p. 49.

to them whether our privacy is respected. We can choose whom to invite to our house but we do not really have control over the behaviour of that person once she is inside. In the case of the friends it may even seem odd to say that we are in control but rather that the norms of friendship give us a context of trust.

Furthermore we normally take ourselves to have control of who enters our house because society is structured around a set of normal expectations that prohibit entering without permission, but in fact we do not really have control over whether someone enters our house without permission. We simply expect and trust that others respect existing social structures and do not enter without permission. We share privacy with others and have certain expectations of how those others will behave. We are not able to regulate the situation as it develops unless other people respect our control – so our control is in fact very weak. Hence it must be recognized how much privacy in fact depends on social conventions and on others' respect for our choices. Our control is therefore always defined against a backdrop of social practices, practices that are different from one society to another or one culture to another.<sup>107</sup>

### *3.2.1 Challenges to the control model*

Inness argues that the control model can deal successfully with the case discussed earlier, in relation to the separation model, where a person crawls under the bed to avoid a peeping tom. According to Inness in this case privacy is violated because the person has lost control of the situation when she is forced to hide under the bed to remain unseen. Again it is helpful to compare this case with buying curtains or building a fence in order to shut out one's neighbours. Those activities manifest the control of the individual in this respect. Similarly one can argue that hiding under the bed is exactly an exercise of control to have privacy. Just

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<sup>107</sup> Maclin (1999).

as I lack control until I buy curtains I lack control of the situation until I hide under the bed. As was discussed in relation to the separation model a reference to social norms and practices is needed. This shows that the control model fails to distinguish successfully between these two cases of hiding under the bed and buying curtains. It is accepted as a control of our privacy to build fences or put up curtains but we should not be forced to hide in closets or under our beds to preserve our privacy.

There are similar concerns regarding disclosure of personal information. One may argue that a person who discloses information about herself experiences a loss of power while the other has gained power to handle the personal information at will. Again this depends on social structure and norms. Some social settings require strict confidentiality such as the doctor-patient relationship; what we reveal to our doctors should not be disclosed to a third party except under special circumstances. In the background there is a social institution which defines how these standards should be met. Similarly a core meaning of friendship is that we can confide and disclose our secrets, trusting they go no further. And, as will be discussed later, we should be able to disclose information to businesses and institutions trusting it will be only used in that particular context.

From the above we see that the control model shares some of the same problems as the separation model but the control model also raises challenges of different kinds. First it has been argued that it is not clear how a person can relinquish privacy according to this model.<sup>108</sup> Voluntary disclosure of personal information is an exercise of privacy according to the control model even though it results in what intuitively seems a loss of privacy. In a society where everyone chooses to disclose all their personal information, they are exercising privacy

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<sup>108</sup> Gavison (1980) p. 349-350.

according to this view, although the result is that no one has any privacy at all! Thus the control model focuses on the power to make choices on private matters rather than the way in which we choose to exercise that power. Therefore it seems to conflate privacy as a condition with privacy as a right one might choose to exercise or not. The person who voluntarily chooses to give up all her privacy does obviously not have privacy anymore but she has exercised her privacy control; “there can be loss of control without a loss of privacy and a loss of privacy without a loss of control.”<sup>109</sup>

Second, the control model, which portrays the individual as having the ability to control the boundaries or access to him or herself, suggests that privacy as control confers upon us an “extraordinary kind of sovereignty”, as Parent argues, for privacy “permits each person to define, unilaterally, his relationships with others.”<sup>110</sup> Parent’s worry is that control of access means that a person cannot exercise his or her privacy unless other persons are affected as well. If someone chooses to give access to herself, the person she gives herself access to is also accessible. This is at least the case when they share space, but not in the case of personal information. So that other person must also be willing to give access otherwise he has been deprived of privacy. This suggests that control of access affects the control of access to the other person as well. Privacy involves others either because they are allowed or denied access. The control model tends to ignore the role of the other in relation to the one exercising control.

Third, the control model fails to distinguish between actual and potential violations of privacy. Parent discusses the following case: “Suppose A invents a fantastic X-ray device that enables him to look through the walls. A then focuses the device on my home but refuses to

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<sup>109</sup> Davis (2009).

<sup>110</sup> Parent (1983a) p. 344.

use it. He has the power still privacy is not invaded. I do no longer have the control”.<sup>111</sup> Here Parent argues that if someone has the potential to violate our privacy thereby we do not have any control. However, if this is the case we have much less control and thus privacy than control-model advocates like to think. We may keep a spare key to our house with our neighbour which gives him the possibility of entering our house when he likes. When we leave the key we do not even have to specify to our neighbour that he is not supposed to enter the house at will: Leaving a spare key means that it is only to use for my advantage. A locksmith might also be able to enter our house, or just anyone with a battering ram or bolt cutter. However this does not mean that we have given up our privacy at home. This shows how the control model fails to capture some important privacy cases. Moreover the control model presupposes individual autonomy and thus excludes those who do not have the capacity to choose for themselves. This point will be taken up in a later section on autonomy.

Fourth, the control model is criticised for defining privacy as the same as control. According to this view, it is one thing to state that control is an important component of privacy; another to say that control is the same as privacy. Privacy cannot be the same as control per se but must be control of a certain kind or control over certain matters. Here the control model refers to the public-private distinction. We must be able to separate these issues we should be able to control.

The distinction between public and private, which is central to the separation model, is not an essential part of the control model, and in Inness’ version of the control model is supposed to “overturn the apparent opposition between privacy and publicity”.<sup>112</sup> She argues that privacy as control grants “the individual control over the division between the public and

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<sup>111</sup> Parent (1983a) p. 344.

<sup>112</sup> Inness (1992) p. 41.

the private with respect to certain aspects of her life. Since an agent can exercise control by choosing to expose private aspects of her life to others there is no necessary antagonism between privacy and publicity”.<sup>113</sup> At the same time Inness argues that privacy as control does not apply to all our lives, but to control over a certain area of our own life or “a specified realm of autonomy”.<sup>114</sup> Although separation between the public and the private is not central to the control model, it presupposes some distinction between the public sphere and the private, which demarcates the realm of control. Or, as will be discussed later, differences between information that is personal or intimate and information which is not sensitive in this respect.

There are further concerns about privacy and control. We often seem to be able to enjoy privacy although it is not necessarily initiated by us, nor do we have control of when the privacy situation ends. Consider students sharing a house together. It makes perfect sense to say that any of them enjoys privacy of the home when the others go out, without having control of when they leave or when they return. The student enjoys privacy without having any control of the situation. Hence privacy can be enjoyed without having control over the situation.

From the above discussion we see the limits and weaknesses of the control model. The control model puts too much emphasis on the ability of individual control in social situations. It is committed to a control that may leave us with no actual privacy – if chosen. It is included in the model to be separated from others in some sense; it is important to be able to control who has access to us and with whom we share our personal information. Therefore a reference to the private sphere is needed. However, neither of the two models sufficiently addresses social practices and the nuanced differences between examples based on social norms and

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<sup>113</sup> Inness (1992) p. 42.

<sup>114</sup> Inness (1992) p. 47-8.

requirements. When examining these two models I have emphasized the social aspect and how social norms define what is regarded as private, and how and whether we are able to enjoy privacy at all.

### *3.3 Two cases of privacy violations*

I now want to examine and compare two extreme cases of a loss of privacy: one of the prisoners in Bentham's panopticon<sup>115</sup> and the other of Truman Burbank in the film *The Truman Show*. These examples illustrate why privacy is significant. I will contrast these examples with crowded societies or the Inuit communities where there is little control by individuals and yet there are social norms that grant individuals privacy within them. This comparison illustrates that the difference does not lie in lack of control of the situation or being exposed to others, but in the way in which we interact in different contexts.

The panopticon was designed by Jeremy Bentham in 1791 as a prison or rehabilitation-home.<sup>116</sup> The panopticon is an annular building, divided into cells with inner and outer windows and side walls. The walls prevent inmates from contact with each other and the lights coming from the outside make them visible at all times. In the centre of the building is a big tower allowing prison guards to observe every single cell and each inmate at any given time. Within this structure the inmates can neither see the guards who are observing them nor can they in fact know if they are being observed at all. They only know that this is possible and in fact likely. Therefore the panopticon is an efficient way to monitor and control the behaviour of the inmates. Whether the inmates are observed at all times or not, they lack privacy in the panopticon.

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<sup>115</sup> Foucault (1977).

<sup>116</sup> Foucault (1977).



Foucault uses the panopticon to discuss total power over people to control or affect their actions.<sup>117</sup> He points out the cruelty of the constant surveillance and how the visibility is secured with backlighting: “They are like so many cages, so many small theatres, in which each actor is alone, perfectly individualized and constantly visible.”<sup>118</sup> The panopticon strips the inmates of interrelations and personal contacts. It is “power reduced to its ideal form”.<sup>119</sup> The idea behind this design was not only total observation but also to control and affect the actions of the inmates; “carry out experiments, to alter behaviour, to train and correct individuals”.<sup>120</sup> Foucault argues that it represents a social power over individuals and his analysis has been used further to explain modern surveillance technology.<sup>121</sup> In both cases the power is total and in both cases there is no interaction between the one who observes and the one who is observed. They know they are being observed without knowing who is observing or if anyone is doing so for that matter. Furthermore Foucault argues that surveillance disciplines the inmates and normalizes behaviour. This is done against a background of acceptable behaviour and tends to turn deviates into perverts.<sup>122</sup>

Another story of constant observation is told in the film *The Truman Show*. It is the story of Truman Burbank and his daily life from the day he is born; it tells about him growing up, his friends, his school performance, and his family relations. The town he lives in is, however, no ordinary town but a giant TV studio, with cameras hidden everywhere and with people acting their roles. He is the subject of an extremely popular TV show and his life is followed in detail by millions of TV viewers on a daily basis. Everyone interacting with Truman is

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<sup>117</sup> Foucault (1977).

<sup>118</sup> Foucault (1977) p. 200.

<sup>119</sup> Foucault (1977) p. 205.

<sup>120</sup> Foucault (1977) p. 203.

<sup>121</sup> Lyon (2006).

<sup>122</sup> Foucault (1977) and Margalit (1996) p. 205.

faking their part or playing their role. This is the only life he knows and he alone does not know the truth about his existence until one day when he accidentally steps outside!

For inmates of the panopticon and Truman there is no privacy; there is a total loss of privacy, at least as far as it is possible today. One can argue that Truman and the panopticon inmates still have their privacy of thoughts but they are accessible in all other respects. In both cases there is total surveillance of every movement and in Truman's case the loss of privacy is more intensive since his life is recorded. Literally everyone can watch him on TV and have access to him and his personal information. There does, however, seem to be some differences worth exploring. The inmates in the panopticon know that they are being observed, or that they are most likely being observed at all times. They can therefore react to that fact and change their behaviour accordingly. In a Sartrean sense of self-consciousness they are aware of the surveillance, which might affect their abilities to relax and be unconscious of the ways their persons are seen by others.<sup>123</sup> Since the surveillance is constant they are denied of this value; their freedom is restricted to the extreme and they have little chance of true personal relations. The purpose of surveillance is to alter the inmates' behaviour, to keep them under control and discipline them. Their private space has been reduced to nothing.

Truman appears to have freedom to do what he likes within his town but he is *deceived* about the fundamental conditions of his life. He does not know that he is being constantly watched, and more cruelly, he does not know that he is a character in a TV show and that the people around him are actors playing their roles. He has more space than the inmates in the panopticon and has more options, but still his movements are manipulated by his environment. Truman thinks he has privacy when in fact he does not. In this sense we can distinguish

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<sup>123</sup> Benn (1971) p. 7.

between inmates who have limited privacy and Truman; and it is because of the deception in Truman's case that his privacy is violated.

Regardless of the deception in Truman's case, he and the panopticon inmates are being manipulated: in Truman's case by the people acting in the show having more knowledge than himself, and the panopticon inmates by surveillance. We may ask if privacy would equally be violated in Truman's case if he knew about his role in the TV series. Deception is an intrinsic part of the Truman show and therefore it is hard to imagine the show going on in the same fashion if he knew about the cameras. There have been TV shows similar to Truman's where people are under constant surveillance for a period of time. In such cases people voluntarily relinquish their privacy. According to the separation model, Truman obviously does not enjoy the condition of privacy as being separated from others, and according to the control model he would paradoxically be exercising his privacy if he had voluntarily agreed to be on the show even though it seems at least intuitively that he has no privacy! This point will be taken up again in the next section on autonomy.

When we violate privacy we intrude into someone's private space without her knowledge or pry into her private affairs; the person is being deceived or exploited. When the private space is limited the person has fewer possibilities to enjoy privacy or even no possibility at all. However, Truman and the panopticon inmates are importantly manipulated and controlled by others, altering their thoughts and actions. This kind of manipulation is also apparent in Orwell's novel *Nineteen eighty-four* where the society is organized in such a way that there is limited or almost no privacy: Big Brother appears on a screen in each apartment, and people's movements are constantly observed in most places.<sup>124</sup> In Orwell's society there is

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<sup>124</sup> Orwell (1989).

a lot of interest in controlling the thoughts of the citizens and the result is, as in the panopticon, total loss of trust. Everyone is suspicious of everyone and worried about being watched and exposed. The lack of social trust makes it impossible to have privacy because privacy must be supported by some social norms as will be discussed in chapter 5. It is the distrust that is important here not necessarily the fact that people do not have control over who sees them. This will become clearer in the discussion of the Inuit community below.

Fortunately the above examples are extreme, although some fear that modern information technology and surveillance is moving in this direction. As Gavison notes, privacy is always already limited in some sense, but it can be limited for different reasons. In crowded societies people may sense little possibility of being alone or withdrawing from others, and there is an important difference between being accessible and being under surveillance. In the case of surveillance the purpose is to control or manipulate, but not in the case of crowded societies. Take, for instance, the Inuit society discussed by Barrington Moore, where the group is crowded in a small igloo leaving each individual little or no private space.<sup>125</sup> Moore argues that there are possibilities of privacy in such a community because there are norms operating, where people give such a space by looking in other directions, seeing without seeing. Surely such a situation can discipline others or change behaviour but the point is that no one is trying to manipulate people in such a way. The difference between this case of the Inuit community and the panopticon is that in the Inuit community everyone is on equal ground. It is in everyone's interest to respect each others' privacy. In the Inuit society a good amount of trust is needed between individuals, creating the possibility of privacy and there are social norms precisely designed to give privacy. In the panopticon no such norms are there to give privacy.

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<sup>125</sup> Moore (1984).

The notion of privacy developed in the Inuit society is neither captured by the separation model, since the privacy takes place with access of others, nor by the control model, since the access of others cannot be controlled. Privacy is not necessarily about having or not having a private space, nor is it about having control; rather, it is about how we interact.

The Inuit community is entirely different from the cases of Truman and the panopticon inmates where social reference to privacy has been eliminated. And the situation is also unlike Crusoe's, being in isolation and away from any social reference. Still, both Truman and the panopticon inmates have been taken out of the social context in an important way and their relations with others represent this fact. There are no genuine social norms in the case of Truman because all interactions with others are faked. Truman trusts the others but his trust is misplaced. In the case of the panopticon there is no interaction with others on an equal basis and thus social norms do not apply. There is no trust and so no privacy is possible.

This discussion has repeatedly raised the issue of trust. For privacy to be protected we need to be able to trust people and institutions around us to respect our privacy, and, as we saw in the Truman case, our trust must be well placed. Another aspect of privacy is that it is reciprocal; it is about personal interaction on an equal basis. We have a mutual interest in privacy and the social norms protecting privacy protect all of us. There is evidence that this trust is fading in modern society, making us more concerned about our privacy. This will be discussed in later chapters.

We see from this discussion the problems with the separation model and the control model. In the Inuit society the control is not in the hands of the individual; privacy is granted by others. And for the separation model, privacy is not necessarily about not being seen or not being observed but how the observation takes place.

### *3.4 The value of privacy: intimacy and autonomy*

The extreme cases of Truman and the panopticon inmates, discussed in the last section, illustrate why privacy is important, and how extensive loss of privacy deprives individuals of important values. Privacy scholars have described these various values in different ways. Gavison sums up the diverse values related to privacy in the following way: privacy offers people important space away from scrutiny; offers freedom from censure and ridicule; promotes liberty of action; promotes autonomy; promotes human relations and intimacy; offers space for creativity, learning and practicing. Hence privacy is not an intrinsic value but is “functional” and promotes other values deeply important for us.<sup>126</sup>

In the literature the focus has been on two categories of privacy values. On the one hand, there are arguments for privacy as valuable because privacy protects personal relations such as intimacy and friendship. These arguments hinge very often on the separation model of privacy or the notion of restricted access to personal space or personal information. On the other hand, there are arguments for privacy as important for autonomy. These relate to the control model of privacy and again refer both to control of personal space and personal information. However this distinction is not clear cut. Inness, for instance, combines the two when she argues that privacy is valuable because it “acknowledges our respect for persons as autonomous beings with the capacity to love, care and like—in other words, persons with potential to freely develop close relationships.”<sup>127</sup> According to Inness control-based definitions of privacy give individuals control over certain private areas or “a specified realm

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<sup>126</sup> Gavison (1980) p. 360. In the literature most writers argue for privacy as an instrumental value or as having functional value.

<sup>127</sup> Inness (1992) p. 95. The connection between intimacy and privacy introduced by Inness depends on decisional privacy and therefore will not be discussed further here.

of autonomy”.<sup>128</sup> Moreover they suggest a distinction to be drawn between sensitive, intimate space or information, and non-sensitive or public ones.

### *3.4.1 Privacy and intimacy*

Many writers on privacy discuss the value of privacy in relation to personal relations and intimacy.<sup>129</sup> Gerstein argues that intimacy depends on privacy or keeping observers away, where intimacy is “an experience so intense that it wholly shapes our consciousness and actions.”<sup>130</sup> When we experience intimacy, according to Gerstein, we sense our actions “only as they flowed immediately from the development of the intimate relationship”.<sup>131</sup> This requires different awareness than we have when we are observed by others. Therefore intimacy depends on not being observed where observation affects our action and destroys intimacy. Furthermore, according to Gerstein, privacy invasion or uninvited observation can also deeply damage the relationship that underlies intimacy. This way of explaining the relation between privacy and intimacy is based on privacy as restricted access of personal space, free from observation.

Another way of describing the relation between privacy and personal relations or friendship is presented by Rachels, who argues that there is a close relation between “our ability to control who has access to us and to information about us, and our ability to create and maintain different sorts of social relationships with different people”.<sup>132</sup> According to Rachels the important factors in forming different relationships depend on how much personal information we are willing to share with others. We are willing to share more of ourselves

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<sup>128</sup> Inness (1992) p. 47.

<sup>129</sup> Gerstein (1984), Inness (1992), Rachels (1975), Reiman (1976). Earlier for instance Fried (1970) argued in this fashion.

<sup>130</sup> Gerstein (1984) p. 265.

<sup>131</sup> Gerstein (1984) p. 268.

<sup>132</sup> Rachels (1975) p. 326.

with close friends than with acquaintances, and we show different sides of ourselves to different people depending on how close we are to people or what role we are playing. This argument for privacy and friendship is importantly based on informational privacy; it is a matter of what we share with others and to what degree.

These arguments for the necessary relations between privacy and intimacy or friendship are problematic and they have been criticized for different reasons. First it has been argued that intimacy does not necessarily require restricted access or absence from observation. The discussion of the Inuits illustrated how intimate actions are possible even in the presence of others, contrary to what Gerstein argues. The essential part is that others “give space” needed for intimacy. In this case the decisive point is *how* the other persons are present in the situation, whether they are simply there not paying attention or are actively observing or staring at the other. Also what matters for the Inuit community is the trust in the social structure. Elliot and Soifer discuss a different example of someone who has a webcam in her home and shows every action of hers both intimate and not.<sup>133</sup> They argue that she may become accustomed to the camera after a while and stop taking notice of it. In such a case the person’s actions are not affected by being observed and her intimacy is not destroyed. One might object to this example and say that a webcam is different from having someone physically present. But that was the case with the panopticon where the inmates were observed without seeing the observer. Again an important difference between these two cases is that the person with the webcam is voluntarily keeping it in her home but the panopticon inmates are in a coerced situation. It is well possible that we can adapt to surveillance in modern times and become just like Inuits, but as I will argue later that may require lots of social trust.

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<sup>133</sup> Elliot and Soifer (2010) p. 492.



Second, the argument that defines friendship in relation to informational privacy is also problematic. Reiman criticises Rachels for what Reiman labels as “a market conception of personal intimacy”<sup>134</sup>. According to Rachels’ view friendship is not based on what we have but also on what others do not have, namely that our friends have confided in us but not in others.<sup>135</sup> This misses the essential point of friendship, which is not necessarily about sharing information, although that is an important factor, but about caring for the other person. Also we share personal information with people outside the context of friendship. We may share our most personal thoughts with our doctor or psychotherapist still such sharing of information does not amount to a friendship or an intimate relationship.<sup>136</sup> It has been suggested that the difference between friendship and our relations with professionals is that unlike professional relationships, friendship is mutual, where both parties confide in each other. Our relationships with professionals are of course not mutual but Elliot and Soifer argue that we can well imagine such mutual sharing outside the context of intimacy and friendship. They discuss an example of two persons who write “tell all” books to illustrate the point. Although both persons do read each other’s book and thus have shared each other’s personal information, a friendship between them has not been established; something more is needed. Another example would be self-help groups online, where people do share intimate information without establishing a friendship.

We see that whether a particular action is intimate or not depends on the social context rather than the nature of the action or where it takes place, just like we saw in the example of exposing underwear in public. Sharing personal information is intimate between close friends but not between a patient and a doctor, and sexual intercourse is intimate between two people

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<sup>134</sup> Reiman (1976) p. 32.

<sup>135</sup> Rachels (1975) p. 328.

<sup>136</sup> Elliot and Soifer (2010) p. 493.

who care for each other but not between a prostitute and a client, and so on. What matters is the social context which defines expectations and possibilities of trust, not where it takes place or what kind of behaviour.

The above discussion shows that it is not possible to establish a necessary connection between privacy and intimacy or friendship. Nevertheless both sharing information and sharing space seem to play a role in establishing intimacy and friendship. Intimacy is normally enjoyed within the private sphere, where we are away from others. What seems to be most important is that we are vulnerable in the situation of sharing our intimate thoughts or intimate actions, and these actions can easily be exploited by taking them out of context or being put in a different light. Therefore we like our sharing to take place in a trusting environment. However that does not mean we cannot enjoy privacy with others around. Having privacy does not depend on whether we are being seen by others but does depend on how we share information and the ways in which we are with other people. These things rely on social norms: what we are required to do or how we are supposed to behave. They are based on our relations with others if we know the observers, if we are on equal “privacy terms”. In the panopticon the inmates are under constant and hostile surveillance and no privacy is possible whereas in the Inuit community people rely on each other to grant privacy.

### *3.4.2 Privacy and autonomy*

One of the prevailing arguments for privacy is that it protects autonomy.<sup>137</sup> The relation between privacy and autonomy has been explained in several different ways and is very often associated with the control model. First it has been argued that privacy as control of personal

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<sup>137</sup> Gross (1971), Beardsley (1971), Kupfer (1987), Rössler (2005). Privacy and autonomy is often explored in relation to constitutional privacy, see for instance Eichbaum (1979) Henkin (1974) and Mindle (1989).

information and private space is a necessary condition for developing an autonomous self.<sup>138</sup> Second it is argued that privacy is necessary to exercise autonomy, since privacy enhances our possibility for self-reflection.<sup>139</sup> I will discuss these two different views below but let me start with some general comments on autonomy.

Generally speaking, autonomy is seen as a condition for freedom. A person who is autonomous is in control of her life and relations to others. She is in charge of her life, able to make her own choices. Joel Feinberg's puts it like this: "his tastes, opinions, ideals, goals, values, and preferences are all authentically *his*".<sup>140</sup> The autonomous person creates herself and is responsible for her own choices, which requires the psychological ability to be self-governing and the ability to reflect and criticize her first-order desires and values.<sup>141</sup> The emphasis here is on the individual and her independence of others. This short description of autonomy presents obvious links to privacy as having control over certain aspects of our lives: autonomy *is* the ability to make choices whereas privacy refers to being in control of certain aspects of our lives.

There is at least one apparent difficulty with associating privacy with autonomy and the ability to choose. An autonomous person is someone who is aware of her options and can evaluate them; she understands that various choices have lasting impact on her life.<sup>142</sup> This means that an autonomous person must have minimal rationality to be able to understand what it involves for her to realize her goals and to plan her actions.<sup>143</sup> Hence autonomy necessarily requires certain mental abilities, abilities we develop as we grow up and we may later lose

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<sup>138</sup> Kupfer (1987).

<sup>139</sup> Kupfer (1987) Rössler (2005) p. 1, Gross (1971), Benn (1971).

<sup>140</sup> Feinberg (1989) p. 32.

<sup>141</sup> Christman (1989) p. 5.

<sup>142</sup> Raz (1986) p. 371.

<sup>143</sup> Christman (1989) p. 12.

because of mental health or age. Privacy is, however, not necessarily connected with mental abilities unless we accept the control definition of privacy and connect privacy with autonomy. However it makes perfect sense to talk about privacy of children, of elderly people, comatose or even deceased people. In such cases others must protect their privacy; similarly, parents must protect their children's privacy.

Joseph Kupfer, who explains the meaning of privacy as control of personal information and control over who can experience or sense us, argues that “privacy is a necessary condition for something of basic value – the development of an autonomous self.”<sup>144</sup> This autonomous self-concept requires that a person is aware of her control over her relations to others and who has or should have access to her. In order to develop an autonomous self others have to affirm the boundaries of the self and they do that by granting the individual control over his movements and information about himself.<sup>145</sup> Therefore privacy is one of the necessary conditions for the development of an autonomous self-concept.

Kupfer cites some empirical studies to show the importance of privacy for developing autonomy and how lack of privacy at an early age may decrease the ability to develop as an autonomous being. Benn cites some studies showing how children raised in a Kibbutz in Israel developed less autonomy than children in other settings.<sup>146</sup> Still these empirical studies are not conclusive and it is not clear if there are such relations between privacy and autonomy.<sup>147</sup> Nor is it clear that greater autonomy equals better life. The kids in the Kibbutz may have better lives for other reasons, such as developing stronger interrelations. The notion of autonomy conveyed here is one of independence but that ignores the value of interrelationships.

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<sup>144</sup> Kupfer (1987) p. 81.

<sup>145</sup> Kupfer (1987) p. 82.

<sup>146</sup> Benn (1971) p. 19.

<sup>147</sup> See also discussion in Solove (2008) p. 81.

Furthermore Kupfer understands privacy as needing private space, but as I argue below this is not necessary for understanding privacy.

Furthermore it has been argued that loss of privacy may lead to loss of autonomy as in crowded hospitals or in totalitarian institutions such as prisons.<sup>148</sup> Therefore Kupfer concludes loss of privacy, defined in terms of personal space and boundaries between individuals, causes limits to autonomy. It is also worth pointing out that in prisons people are objectified making genuine relations next to impossible. As Kupfer himself points out, this argument relies on empirical studies not altogether conclusive. In some of the cases Kupfer discusses, like crowded hospitals, patients may have already developed autonomy but are experiencing its temporary loss because of their illness and lack of options in this particular situation. Once they get well again their autonomy may be functioning again.

Kupfer argues not only that privacy is important in developing a basic autonomous self-concept, but also that privacy “enables self-knowledge, self-criticism, and self-evaluation”, necessary for exercising autonomy.<sup>149</sup> This form of control is second-order autonomy. According to Kupfer we need a sphere of privacy to try things out and exercise self-criticism which enables us to enjoy greater autonomy. This is so because a person who exercises such self-criticism has more self-knowledge and is therefore better able to make choices and decisions truly her own. We are more autonomous if we carefully evaluate our lives and developed self-reflection gives us more control over ourselves.

However, relating self-criticism to privacy, in the way Kupfer does, suggests that we develop our autonomy alone but not in relations with others. The idea here is that we come to know ourselves when we have space to evaluate our lives in solitude. Surely solitude is often

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<sup>148</sup> Iris Young makes this point for elderly people see Young (2004). See also further discussion in chapter 2.

<sup>149</sup> Kupfer (1987) p. 83.

needed to reflect on one's life and experiences, but the contrary is also true. The presence of others, conversations with friends or professionals and other interactions may just as well stimulate self-reflection or self-criticism. Sometimes we may know what we should do in a particular situation when we reflect on it in our solitude but that does not mean we will be able to execute our decision against or surrounded by others. Take someone who wants to quit her job and make changes in her life. She might be determined to do so after solitary contemplation but she might not have the strength to tell her family or partner, being afraid of a negative response. Therefore the strength of our autonomy or our ability to withstand pressure or coercion is tested when we are with others but not when we are alone.

Kupfer relates this second understanding of privacy and autonomy to trust. When persons are given freedom from surveillance, it suggests that others find this person trustworthy – worthy of being alone, just as parents allow their children to be alone once they are mature enough and can be trusted. According to Kupfer “privacy is a trusting way others treat us, resulting in a conception of ourselves as worth being trusted”.<sup>150</sup> In turn the person must act responsibly when granted privacy.

Therefore Kupfer emphasises autonomy both as independence from others and also discusses autonomy as a social product. He argues that it depends on the social context how much control each individual is allowed to develop, and it is necessary to have control of others' experience of us to be able to develop as self-determining individuals. Not all societies allow for such a development. Autonomy requires certain practices and Kupfer argues that societies that do not value autonomy do not value privacy either.<sup>151</sup> It might well be the case that autonomy requires privacy, in the meaning of control, but that does not mean that privacy

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<sup>150</sup> Kupfer (1987) p. 85.

<sup>151</sup> Kupfer (1987) p. 82.

needs autonomy. We can enjoy privacy without being autonomous or being in control. In a society where there is not much private space or control, there still may be an understanding of privacy to some degree.

James Stacey Taylor examines Kupfer's and Benn's arguments and the strong claim that violation of privacy undermines individual autonomy. Taylor's main criticism is that Kupfer and Benn fail to distinguish between overt violations of privacy, when the person realizes that her privacy is being violated, and covert violations when the person is oblivious to the fact.<sup>152</sup> He argues that this distinction is important for autonomy and privacy because covert surveillance does not necessarily undermine autonomy even though it violates privacy. This means that we can have covert violation of privacy without autonomy being undermined. Taylor does not explicitly deny that autonomy might be undermined in the case of covert surveillance, but argues that a violation of privacy will only result in undermining one's autonomy if other conditions are also met: The person who is being watched would behave differently if she knew she was under surveillance, and she must be unaware of the fact that she is being watched. The surveyor can decide whether he reveals himself or has "control over whether or not his victim believes that she is being watched".<sup>153</sup> The surveyor must be able to let the subject of surveillance know she is being watched and he must have the intention of controlling her. The person watched must be likely to respond to the violation as she might simply not care if she is being watched or not. Therefore according to Taylor we cannot establish a necessary relationship in this sense but only a contingent one.<sup>154</sup> If these conditions are met, violation of privacy may undermine people's autonomy – otherwise not.

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<sup>152</sup> Taylor (2002) p. 587.

<sup>153</sup> Taylor (2002) p. 594.

<sup>154</sup> Taylor (2002) p. 596.

I have already discussed the case of Truman and the panopticon, both cases of extensive surveillance. There I argued that although the panopticon inmates do know of the surveillance but Truman does not, in both cases the surveillance affects their behaviour. The two cases of Truman and the panopticon show that Taylor makes too much of the difference between overt and covert surveillance. In both cases there is extensive surveillance and with it, in both cases, comes manipulation. We can well think of a case where finding out that someone is being watched does not affect autonomy. Hence privacy can be invaded without autonomy being compromised.

Again what matters are the circumstances and social norms. According to the control model of privacy, individual control is the central part of privacy. Privacy is the ability to choose when to be alone, what to share with others and so on. Examining the relations between privacy and autonomy shows that it is at best complex. Autonomy is the ability to choose but privacy involves certain kinds of choices. According to Kupfer, privacy is a condition for being able to choose in the first place. This understanding seems however to subscribe to a broader notion of privacy than the control model accepts. Even though violation of privacy may undermine autonomy in some cases, as Taylor points out, this is not always the case. Furthermore we can surely say that a person can enjoy privacy even in a situation that is not fully chosen. As I have discussed, there are many ways of violating or limiting a person's privacy without affecting their autonomy. Also, as Kupfer does imply, the way we develop our sense of boundaries depends on social practices and norms; the understanding of privacy depends on others.

In this section I have examined arguments valuing privacy for protecting autonomy and intimacy or friendship. These arguments have been criticised from different angles and they



show that strong connections between privacy and these different values cannot be established. We have seen that privacy plays a role to an extent in establishing friendship and intimacy, but there are also cases that do not rely on privacy. Same was the case with autonomy. What matters is not necessarily whether we are being observed, but how we are being observed. In this case trust is an important component of privacy as promoting both intimacy and autonomy. There are relational aspects of privacy that are unlike our understanding of autonomy.

### *3.5 Privacy as a social concept*

We have seen that the two prevailing models of privacy, the separation model and the control model, fail to deal successfully with many important privacy concerns. This will become more apparent when we discuss informational privacy and information technology in the next chapter. My main criticism of the separation and control models is that they do not take social norms and social structure into account. In this section I will sketch an alternative view: privacy as a social concept.

#### *3.5.1 Privacy in a social context*

Although privacy is, as we have seen in the discussion of different models, associated with the sphere of non-interference and the public-private distinction, few writers within the privacy literature have related privacy with social norms or social practices. There are, however, exceptions. Ferdinand Schoeman, in his book *Privacy and Social Freedom*, distinguishes between two aspects of privacy: *privacy from* and *privacy for*.<sup>155</sup> *Privacy from* involves restrictions on others or isolation. This understanding refers to the need for private space. And according to Schoeman we need restricted access to form relationships with family and friends or experience intimacy. In the case of *privacy for* he identifies different spheres for different

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<sup>155</sup> Schoeman (1992) p. 156.

relationships. According to Schoeman, we move among various spheres of life and what is appropriate to reveal in one sphere may not be appropriate to reveal in another. Another writer, Robert C. Post, in a paper where he examines privacy in US tort law, argues that at least two of the four distinct branches of privacy torts deal with the interdependence of persons and social life, but not the opposition between the two.<sup>156</sup>

More recently, in their analysis of information technology, privacy scholars have introduced broad accounts of privacy that are grounded in social contexts and social practices.<sup>157</sup> Daniel J. Solove understands privacy in relation to Wittgenstein's notion of "family resemblances". This means that the concept does not have a single common characteristic, but rather several different ones.<sup>158</sup> Helen Nissenbaum argues for a framework of privacy as contextual integrity, where she refers to the use and context of information, and she argues that the main concern people have for privacy is not that information is shared at all but that practices "transgress context-relative information norms".<sup>159</sup>

Nissenbaum does not see her account of privacy as radically different than traditional theories but rather as an attempt to fill a gap she finds missing.<sup>160</sup> This gap has to do with how we deal with many technological challenges and the flow of information. According to her, the right to privacy is a right to context-appropriate flows; privacy depends importantly on reasonable expectations we may have of how information is used in different contexts and can apply to all areas of life, both public and private. These different realms of our lives are defined by different sets of norms that govern, for instance, information about people. Accordingly, norms of appropriateness define what is fitting to reveal in particular contexts,

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<sup>156</sup> Post (1989) p. 959.

<sup>157</sup> Solove (2008), Nissenbaum (2010).

<sup>158</sup> Solove (2008) p. 9.

<sup>159</sup> Nissenbaum (2010) p. 186.

<sup>160</sup> Nissenbaum (2010) p. 3.

and norms of distribution define how information should be transferred between different spheres of life. These sets of norms define our expectations of what is shared and with whom – that we live in a world “in which our expectations about the flow of personal information are, for the most part, met.”<sup>161</sup>

Nissenbaum is primarily interested in how information flows in the modern computerized world, and how the technology transforms the public through surveillance. Information technology and its effect on the public will be discussed further in the next chapter. However, as I have argued in this chapter, questions of privacy in public do not only arise in relation to information technology. There are numerous social norms that are supposed to protect our privacy when we ride on the bus or have a quiet conversation in the park. Therefore, we can meaningfully argue that personal information available in the public sphere should have some privacy restrictions. What matters is how the information is used and in what context.

### *3.5.2 Privacy as a social concept*

I have argued in this chapter that privacy is deeply embedded in social norms and conventions. Whether it is appropriate or not to look into a window or listen to a conversation depends on the social structure, what norms are in place, and what expectations we may reasonably have of others' behaviour in a social context. We have seen that both the separation model and the control model fail to distinguish successfully between situations where a person gets curtains to prevent a peeping tom from looking in her house and the one where she hides under the bed to prevent him from access. In both cases the person is inaccessible and in both cases we can say that she is exercising control of the situation by setting up curtains or hiding under the bed.

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<sup>161</sup> Nissenbaum (2010) p. 231.

The difference between the two cases must be explained in relation to social structure. Putting up curtains is an acceptable way to protect our private space and should be respected by others – we should not be forced to take such extreme measures as hiding under the bed to protect our privacy.

I have argued that privacy is not defined unilaterally by individuals but is defined in relation to others with regards to personal space or information. Privacy does not apply in situations where an individual is in isolation or solitude but depends on the relation to others. In the case of Robinson Crusoe there is no reference to others and privacy does not have a place. This means that privacy is a *relational* concept. Privacy is an important value in structuring relations between individuals or social institutions. These relations take on different forms – some of them are formal and structured, others are more informal. In some cases, like intimate relations, privacy is a fundamental value; in other cases the privacy relations are less important.

Our roles and relations are structured by social norms or conventions to a large extent, whether the relations are defined by being a neighbour, a parent, a partner or a friend. When we are invited into someone's house we are in the role of a guest. This role defines what behaviour is appropriate: we are allowed to look at things but not open drawers or closets. Similarly, privacy is an important feature of friendship, where we share information and give each other space. We do not spell out privacy in our relationships with our friends; rather, it is implicit in a set of norms that defines friendship. A more formal relationship exists between a doctor and a patient, and is defined by social institutions. When we share personal or intimate information with our doctor we expect him to keep strict confidentiality. Social institutions such as professional organizations define how these standards should be met.

Whether we are inviting a guest to our house, or share information with our friends or our doctor, we are not limiting our privacy or experiencing loss of privacy; rather, we are exercising privacy. We trust that our friend and our doctor will respect the social norms defining these different contexts. According to this understanding of privacy, it does not matter how much information is shared – it still makes sense to talk about privacy. In the Inuit society a great deal is shared between people, but still there is a place for the others to give space, see without seeing, and as such respect privacy. As long as our guests, our doctor or our friends comply with the privacy norms and rules entrenched in our social institutions, there is no privacy violation or limit of privacy.

Rather than defining privacy in relation to expectations we have about the flow of information, as Nissenbaum argues, my account defines privacy within social roles and institutions. This means that enjoying privacy depends on how the relationship is defined and what expectations we have for behaviour on the part of the other. As will be discussed in chapter 5, this understanding of privacy is importantly related to trust or trustworthiness — that we can trust others to comply with the rules or social conventions in place. The doctor needs to be trustworthy to be able to do his job and hence the profession needs to be trustworthy: we need to know that there are standards within the institution that define the doctor's behaviour. Trust is an important component of that social institution. According to this view the burden of privacy is not only placed on the person who shares information; it is also placed just as much, or even more so, on the receiver. Privacy must be defined between the individuals, or between individuals and institutions, where the other has obligations to respect privacy. How privacy depends on trust and obligations will be discussed further in chapter 5.

According to the control model we can exercise privacy without having the condition of privacy. Consequently, if a person voluntarily shares everything about herself, she still has privacy since the information was voluntarily shared, although this means that she no longer has any privacy. According to the social model privacy does not depend on information we have for ourselves or space of restricted access, but is about sharing information and space. Therefore we are not compromising our privacy or experiencing loss of privacy when we share information or space. Thus it immediately directs our attention to the protection of privacy and the environment of sharing. Does the sharing of information or space take place within a trusted environment? Are there social norms or structure that we can expect to define behaviours of others?

Social norms that protect privacy are dynamic. They can be different from one society to another, or from one generation to another, and they change with new technology or with more knowledge. Before the discovery of the DNA structure there was no reason to have privacy concerns in relation to our bio samples. However, the risk for particular diseases can be predicted from genetic information, and therefore bio samples are now thought to contain some of the most sensitive information about any individual. In addition, the sensitivity of genetic information must be understood in relation to social background and the structure of the society: the health services available, the importance of private health insurance and which groups are most at risk of being discriminated against. These issues shape the concerns and the new social norms needed to meet those concerns. The issue of genetic information will be taken up in the next chapter.

From this sketch of privacy as a social concept, we see that we do not have a unified concept of privacy. The examples I have discussed are about relations between people and

how we present ourselves differently in different relationship. Therefore privacy is interpersonal. It is defined by interaction between the person who is enjoying privacy and the person or institution that has particular obligations, the one who is trusted not to interfere, not to share the information with others, and so on. Social norms govern these interactions and define these obligations. A society with hardly any privacy is a society of suspicion, where people think that information about them will be used to harm or shame them. In such a society we can have secrets but not privacy.

### *3.6 Conclusions*

In this chapter I have examined two of the prevailing models of privacy, the separation model and the control model. The discussion has shown that they are inadequate to explain important aspects of privacy and fail to explain cases which are intuitively important for privacy. The important connection between the separation model and private space makes privacy in public a contradiction. However, we have seen how important it is to have ways to protect privacy in public. We have also seen that privacy is importantly different from secrecy, seclusion and isolation.

The control model highlights individual control of private things and space. Examination of the control model illustrated how little control we have in many cases where we believe we have privacy, therefore it is quite possible to enjoy privacy even if we do not have control over when our privacy starts or finishes. Furthermore the control model leads to the unhappy conclusion that we can voluntarily decide to share all our private things and space and still have privacy according to the model. A comparison between the several cases of extreme privacy violation on the one hand and with the Inuit community on the other illustrated vividly how privacy is not about control or space of restricted access but about how we interact and

social structure. In section four I examined the value of privacy in relation to intimacy and autonomy. There we saw that privacy is related to both even though we cannot establish a necessary connection. Rather their relation depends on context.

This discussion has shown that privacy interests are broad and deeply entrenched in social conventions and norms. In the last section I proposed privacy as a social concept as an alternative account. Privacy is something we have because we are in complex relations with other people — close friends, professionals, neighbours, strangers or the state. How much privacy we can enjoy depends importantly on the structure of these relations and what kinds of norms are in place. These social norms both define the limits of privacy and possible threats to it.

The examples I have discussed in this chapter are mostly examples of informal relationships. In the next chapter I will discuss some important challenges we face as a result of information technology, such as surveillance technology and accumulation of data in databases. Then we will see more clearly how little control we have of our personal information and how difficult it is to keep information within restricted access, let alone distinguish between sensitive and non-sensitive information. Moreover we will see more profound challenges to privacy in public.

It is customary when describing the division between the public and the private to picture us as physical beings moving from one sphere to the other. With information technology and cyber-space this is no longer the case. There we can move around leaving traces; we can be seen without necessarily seeing others; and we can hide our identity and presence unlike in the physical world. This is transforming the distinction between the public and the private in profound ways. I will now turn to these issues.





## **Chapter 4: Genetic Information and Information Technology**

The literature on privacy has, from the beginning, been reacting to the development of modern information technology. Information technology which enables massive surveillance, distribution of information at lightning speed around the world, and enormous databases is now seen as the major threat to privacy. In the last chapter I examined two traditional models of privacy, the separation model and the control model and introduced a third one, the social model, or privacy as a social concept. The social understanding of privacy focuses on how privacy is shared between people and the role of social norms and practices in understanding and protecting privacy.

In this chapter, my focus will be on the challenges of information technology to the traditional privacy models, which highlight the importance of being able to keep information away from others or the importance of individual control over personal information. To explore these issues, I will primarily be focusing on health databases containing genetic information. This will give me an opportunity both to examine the technology which makes it hard for individuals to have control and to examine the nature of personal information, or to what extent we can distinguish between sensitive and non-sensitive information. Both these issues help to explain how the separation model and the control model are inadequate to meet the challenges of information technology. Instead, the challenges of information technology demonstrate how privacy concerns are concerns about how information is shared or protected in relation to other people and institutions.

To explore the threats of information technology to privacy, I will examine the case of the Icelandic Central Database Complex planned by the private company deCODE Genetics some years ago. Health databases and biobanks are interesting cases to examine for at least two reasons. First, they contain information on health and genetics, often regarded as the most

sensitive personal information. Analysis of genetic information shows, however, its complexities, which again raises the question of how well we can in fact differentiate between sensitive and non-sensitive information. In addition individual health and genetic information, as is true of all kinds of personal information, not only reveals information on one particular individual, but also his or her relatives. This means that individual control of particular information is not the only thing that matters, which brings me to the second issue: the development of information technology or electronic databases. Information technology decreases individual control of information substantially. Information stored in databases or on the internet becomes immediately accessible to numerous other people and possibly used in different contexts. Also, the aggregation of information increases the tendency to treat individuals as members of groups with data mining and profiling.

The chapter will proceed as follows. In the first section I will discuss personal information and what makes information sensitive. Then I will introduce two different models of how we understand information: the container model and the agency model. The container model sees information as a kind of property that can be separated in different ways. Thus this model underwrites the distinction between sensitive and non-sensitive information and the belief that we can control the former. The agency model on the other hand highlights the communicative aspect of information — how information is communicated between people, and depends on social norms.

In the following section I will introduce the Icelandic database complex, where the idea was to construct a complex of three databases with the possibility of combining genetic, genealogical and medical information of the Icelandic population for extensive research in genetics and medicine. Examination of the database illustrates the difficulty with both the

control model and the separation model of privacy. The main problem for the control model is how problematic it is for individuals to be able to control for themselves the use of their personal data. For the separation model the main problem lies in the difficulty of distinguishing between private or sensitive information on the one hand and merely public or accessible information on the other. This will be more apparent in the discussion of genetic exceptionalism in section 3 and examination of different kinds of data. Instead of highlighting the possibility of separating non-sensitive information and sensitive information, I argue that what matters is how information is used and interpreted, as the agency model of information suggests.

In the fourth section I will discuss a few of the numerous threats to privacy arising from information technology per se, with the possibility of storing enormous amounts of information and with endless ways of shifting it between different contexts. I will focus on the privacy issues arising from data mining, profiling and how information technology is transforming the public sphere. Monitoring the public sphere, e.g. with street cameras, raises issues of privacy in public, blurring the line between the public and the private space.

Some have argued that information technology both introduces threats to privacy, and also provides valuable tools to empower individuals and give them control over their personal information. An example of such an argument is presented by Judith Wagner deCew where she argues that the model of caller ID can be used to empower individuals if applied to medical information. In the final section I will examine her argument.

This chapter shows the complexity of privacy issues in relation to personal information and information technology. We cannot easily categorize a set of personal information, such as genetic information, as sensitive or non-sensitive; it depends on the context and social

structure. Furthermore the information technology demonstrates clearly how little control we have for information we share with others or with institutions. Therefore, the conclusion of this discussion is that the traditional ways of thinking of privacy — the separation model and the control model — cannot adequately meet the challenges of information technology.

#### *4.1 Personal information and private information*

We live in a society where personal information has become more and more valuable for individuals, corporations, institutions and the state. Information on financial status and consumer behaviour is used in business marketing; health and genetic information is valuable for medical research and insurance companies; and information on drug use and medical conditions is valuable for employers, to name but a few examples. Because of the growing interest in personal information many see privacy first and foremost as informational privacy, or “as control over what other people can know about oneself”.<sup>162</sup> However, it is hard to keep track of our personal information and therefore many claim that sensitive or intimate information warrants special protection.

##### *4.1.1 Sensitive or personal information*

Generally speaking, personal information can be understood in a broad sense as any information concerning a particular person. This can be information as diverse as the person’s name, nationality, sexual preferences, consumer habits, financial status or family relations. Some information is easily available or is information that we do not conceal: our name and address is in the phone book; our appearance such as skin-colour, eye colour, fashion taste, and height is readily available to anyone who sees us; many willingly share information about their marital status, social status and opinions on Facebook. Thus personal information is not

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<sup>162</sup> Rössler (2001) p. 111.

necessarily tantamount to private or sensitive information. Some of this information we simply share when we are with other people. In other cases, our willingness to share information may depend on social structure, social expectation, or personal preferences.

A more narrow understanding of personal information defines it as private or sensitive information. In the privacy literature personal information is often understood in this sense; it is information that people might not want others to have access to, or information we are entitled to keep to ourselves. William Parent argues that personal information consists of facts which most individuals in a given society at a given time do not want widely known about themselves.<sup>163</sup> This requires a wide consensus on what should and should not be regarded as private. However, as has been discussed earlier, norms on privacy protection cannot only vary from culture to culture but also between individuals. Some people are ‘open’ and willing to share their intimate experience with strangers; others want to keep a lot to themselves, which may generate from different temperaments or even political outlooks. Therefore, we might have various different perceptions on what is sensitive or what is not within the same society.

There are two main reasons that are given in the literature for demarcating between sensitive and non-sensitive information.<sup>164</sup> First, some information is intimate or originated from the private sphere or the private space, while other information is simply public. We have already seen in chapter 3 that informational privacy is often interrelated with the interest of limited access. DeCew states, for instance, that privacy based on accessibility overlaps with informational privacy since obtaining information on an individual involves gaining access to

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<sup>163</sup> Parent (1983) p. 270. Parent is often categorized in relation to the separation model, see Powers (1996) p. 377, but he has also been categorized as presenting an ignorance theory Matheson (2008) and Davis (2009).

<sup>164</sup> Nissenbaum (2010) p. 122-124.

the individual or his or her personal space.<sup>165</sup> The private space or sphere is the locus of intimacy and personal relations and therefore access to the personal space may be sensitive to the individual, especially if it is done without his or her consent. Therefore this understanding of sensitive information depends on the public-private distinction discussed in chapter 2.

The second reason for protecting sensitive personal information is because revealing it might be harmful, cause embarrassment, or stigmatize individuals or groups. For instance, general health information is sensitive in many societies, and more so where people have to rely on private insurance than in societies where there is public health insurance. Furthermore, particular health information, such as information on mental health is regarded by many as highly sensitive, partly because of the stigmatization associated with mental illnesses. This shows that what is harmful in this sense may depend on social structure, which groups are socially weak, or what behaviour is tolerated and what is not.

I believe that the focus on the distinction between sensitive and non-sensitive personal information is leading us away from the real issues. Not only is it very difficult to come up with a criterion that distinguishes sensibly between such kinds of information, but it also turns out information that is generally thought to be non-sensitive can become sensitive in a different context or a different situation. With computerized databases shifting information between contexts has become easier. As we will see later, information on genealogy is regarded as public and in some societies easily available. Nevertheless it can provide information on a person's health status and possible risks, information that might be welcomed by insurance companies. Moreover, with the help of information technology such information can be data-mined and further manipulated on an unprecedented scale.

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<sup>165</sup> DeCew (1997) p. 76.

In a society where the costs of revealing personal information are high, privacy protection is more valuable than in a society where the costs are relatively little or none.<sup>166</sup> In a society where the cost of health service is high it is valuable for individuals both to have access to health insurance and not to have to pay too much for it. With increased knowledge of our genetic make-up, we know more about the genetic origin of some diseases and such knowledge can be used to discriminate between individuals.

#### *4.1.2 An alternative model: the agency model of information*

It is traditional to think about information as “a commodity” or “an intellectual property”. However, information is a commodity of a special kind because it is abstract and can be copied with hardly any cost.<sup>167</sup> This means that information can be stolen simply by being copied without the owner noticing anything missing. Similarly, when we sell information it might still remain in our possession as a copy or in our head. When information is sold, stolen or shared we do not have control over it anymore. Publication of science research is a way to share information with others and then also an individual’s control has been given up to an extent, even though there are social rules and norms regulating how such information may be used. Also, unlike other property, which we can make public temporarily, once information has been published it cannot be unpublished again. Others have gained knowledge or have acquired the information and this knowledge cannot be taken away from them, although they can be prevented by law from using the knowledge for certain purposes – e.g. for profit.

The model of information as “a piece of stuff out there” has been criticized by Neil C. Manson and Onora O’Neill.<sup>168</sup> They criticize the way information is treated both in regards to

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<sup>166</sup> Friedman (2000).

<sup>167</sup> Rosenberg (2000).

<sup>168</sup> Manson and O’Neill (2007).



informed consent and informational privacy. Also they target the idea of information as a possession or as a parcel delivered from one place to another as being a very limited view of information. This description of information focuses on its content and is very much present in the metaphors embedded in the literature, where we talk about disclosure of information and how information is stored or conveyed between individuals. Manson and O’Neill label this model the *conduit/container model* and argue that this way of seeing information overlooks the important aspect of communication in relation to informing and information. This understanding also hides the communicative aspect of information and indicates that information is “already there, that is then to be put across”. It sees information as existing independently of the process of communicating it.<sup>169</sup>

Instead, Manson and O’Neill argue for an *agency model* of information that takes into account “the importance of the rich set of background commitments and competencies that are essentially involved in the activity of communication”.<sup>170</sup> They highlight several features that are essential for communication, features such as seeing communication as a social activity that draws on many norms that shape and structure our speech. Informing is context-dependent and depends on the understanding of the participants in the communication, what they want to do and are capable of doing. Also our communication can be referentially opaque when the audience does not have full understanding of the reference we are making. Furthermore communication is inferentially fertile and enables participants to make a variety of inferences and in fact depends on such interpretation of the audience. And communication is audience-

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<sup>169</sup> Manson and O’Neill (2007) p. 38.

<sup>170</sup> Manson and O’Neill (2007) p. 39.

sensitive in the sense that it requires attention from the audience and often we need not only absorb information but be engaged when receiving it.<sup>171</sup>

We can take an example of a conversation between a doctor and a patient to illustrate these essential features of communication. The doctor may think that by giving the patient some information, or stating some facts about the patient's illness, he is informing the patient properly. How the patient understands what the doctor says depends on the context: how the doctor phrases his thoughts and how the patient understands them. The patient might not be capable of understanding all of what the doctor says, both because of lack of knowledge and because of emotional status. How well the patient understands also depends on the structure of the doctor's speech, and how well he complies to norms that both of them relate to. His words may also be chosen to mitigate the shock he expects his patient to experience and therefore he might mislead the patient. The doctor might even choose his words in such a way to persuade his patient to accept certain kinds of treatment, and he may choose the words in such a way because he knows that the patient does not have the background information needed to fully understand what is said. In spite of the intention of the doctor to convey a certain understanding of the situation to his patient, the patient may still understand the doctor's words quite differently.

From this we see how the agency model stresses that communication is an activity requiring interaction between individuals. Rather than describing the doctor as giving the patient information, where information or facts is moved from him to the other person, informing is a complex communication that requires engagement from both the communicator and the receiver. In such an interaction there is never full control of how the person receives

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<sup>171</sup> Manson and O'Neill (2007) p. 41-48.

the information or interprets it. Furthermore, the agency model depends on social norms and expectations: “Communication is a normative affair that presupposes a rich framework of *shared* norms, and shared background commitments (practical and cognitive), as well as the requisite *inferential* competences.”<sup>172</sup> Subsequently, failure in communication is often due to different understandings or knowledge of these norms, for instance because of cultural differences. I have argued that privacy must be seen in relation to how we share information together and the importance of social norms. Furthermore this suggests that privacy must be seen in relation to communication.

The agency model is not introduced to replace the container model but rather to show two different ways of thinking about information.<sup>173</sup> The container model looks at information as static but the agency model sees it as dynamic, with an emphasis on the social background and how information is communicated between people. Both the separation model and the control model rely on the container perception of information; they see information as something that we categorize in different containers or control from one sphere to another. This understanding is not adequate to deal with modern challenges such as computerized databases, which will be discussed further in section 4.

As we have seen the agency model highlights how information is used and communicated rather than focusing on the content. For privacy protection it is precisely the use of information that is of interest. We cannot put information neatly in separate boxes as being either sensitive or non-sensitive: rather, it depends in many cases on the context and background knowledge of the receiver whether the information is sensitive or not. However, privacy defined both as restricted access to information or control of personal information

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<sup>172</sup> Manson and O’Neill (2007) p. 65.

<sup>173</sup> Manson and O’Neill (2007) p. 48 and 65.

relies on differentiating between sensitive and non-sensitive information because it involves control over particular sets of information. The underpinning is therefore the idea that information is moved like a piece of property from one place to another – from individuals to databases.

#### *4.2 Health databases and biobanks: challenges for privacy<sup>174</sup>*

The merger of information technology and genetics made way for genetic and genomics research on an unprecedented scale. The Icelandic parliament passed a bill at the end of 1998 authorising construction of a Health Sector Database (HSD). The database was to include all medical information about the Icelandic population found within the Public Health Sector. Two years later deCODE Genetics, Inc., a private company, which had played an active role in forming the bill, received a license to execute this project even though the database was to be owned by the state. Constructing the HSD database was part of a bigger project combining different sets of data. The project was seen as a unique opportunity for a private company to do valuable genetic research on a small, homogenous, and well-defined population. As expected, this decision was received with both enthusiasm and dismay.<sup>175</sup> Along with the Icelandic project, similar ones were launched in other countries.<sup>176</sup> Although some of the original plans have come to a halt, or at least changed considerably, and the construction of genetic databases does not attract the same media attention as before, human genetic databases are a main source of providing data for research in medicine and human genetics.

The project raised urgent questions of a political, legal, social and ethical nature. Some of the most controversial issues concerned privacy and informed consent: whether informed

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<sup>174</sup> This section and the next are partly based on Nordal (2007).

<sup>175</sup> This project has come to a halt but database research flourishes within DeCODE Genetics.

<sup>176</sup> Häyry et al. (2007).

consent, the traditional concept of research ethics, should be required or whether presumed consent should suffice; whether privacy could be satisfactorily protected or information secured. There were also questions of who would have access to the information, whether participants would be identifiable when data would be used, and what implications constructing such a database would have on doctor-patient confidentiality. Medical research depends on participation of the general public and the project raised important questions of trust and trustworthiness. Then construction of biobanks raise the issue of benefit sharing: how benefits and burdens arising from medical research and genetic research should be distributed. Then there are dangers of using such population-based databases as grounds of discrimination against individuals or groups.<sup>177</sup> In this section I will start with a general discussion of the Icelandic project and what kind of personal information it contained. In the second half I will discuss the ethical issues of privacy and consent.

#### *4.2.1 The Icelandic Central Database Complex*

There is a long tradition of database research in Iceland and the plan to construct the HSD had its predecessors. This time, however, the project was on a grander scale than before and received wide international attention. At the time the project was being launched faith and expectations in genetic research were increasing. The mapping and sequencing of the human genome, the Human Genome Project, was about to be realized, raising important ethical questions regarding the implications of this new knowledge both for individuals as well as the human population in general. The HSD was to include medical records for the Icelandic population, found within the publicly-owned health care system. These records, which can be traced back some generations and give unique information on the population, were to be put

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<sup>177</sup> Häyry et al. (2007).

into electronic form. Not only was a database with medical records to be constructed, data from the HSD could be cross-referenced with genealogical data on the one hand and with genetic data on the other.

The whole project comprised, in fact, a cluster of three databases sometimes called the Icelandic Central Database Complex (ICDC), and was to contain three different sets of personal data.<sup>178</sup> These data sets are different with regards to privacy. Generally, medical records are believed to contain highly sensitive information on individuals, such as information on diagnoses, treatments, drug use and even lifestyles of patients. Not only is the information taken to be sensitive in kind, but it is revealed in the confidential setting of the doctor-patient relationship. It was therefore highly controversial whether presumed consent would suffice as the bill stated, or if informed consent was necessary to meet ethical standards.<sup>179</sup> In addition to the presumed consent an opportunity was given to people to opt out of the database and it turned out that around 20 thousand Icelanders, or 8% of the total population, exercised that opportunity.<sup>180</sup>

Another part of the database complex contains genealogical information on the Icelandic population, based on public records that have been well kept throughout the centuries. This part has already been constructed and is partly accessible on the Internet to the public in a database called *The Book of Icelanders*. It has been estimated that the total population of Icelanders since settlement in the 10<sup>th</sup> century is 1.5 million, and data on approximately 1.2 million people is to be found in *The Book of Icelanders*.<sup>181</sup> Much of the information in these records and genealogies has been readily available in Iceland for a long time, published in

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<sup>178</sup> Árnason (2004).

<sup>179</sup> Kristinsson and Árnason (2007).

<sup>180</sup> It is ironic that now some years later only the database of the opt-outers is available since the HSD has not been realized.

<sup>181</sup> The current population of Iceland is approximately 320 thousand.

books and papers throughout the years, which manifests a great interest in genealogy in Iceland.<sup>182</sup> The content of *The Book of Icelanders* is regarded as public knowledge, so no consent is needed from individuals and there is no possibility of opting out. Although, as I will argue later in this chapter, *The Book of Icelanders* contains personal information on par with some of the sensitive information found in the other databases, its existence has been well received by the Icelandic population.

The third part of deCODE's database complex includes genetic data and contains blood samples collected through genetic research in the past decades. The recruitment has been based on broad consent, which allows for use of these samples in future research. This database or biobank has been growing fast, and already half of the current population has donated their biosamples. So far two parts of the database Complex are up and running: the Book of Icelanders and the biobank. These two have been the basis of the valuable research in genetics of deCODE. The HSD, however, came to a halt early on and has not been realized.<sup>183</sup>

#### 4.2.2 *Informed consent and biobanks*

It is evident that the data the three databases contain are treated differently with regards to privacy and individual consent. In some cases people have given their consent, which is an exercise of control; in other cases no consent is required. The database with the genealogical information is, unlike the HSD and the biobank, public to a large extent and based mainly on public records or information publicly available. Therefore individual consent was not required. It was, however, highly controversial what kind of consent should be used for the HSD. First, it was debated whether presumed consent would suffice, both because of the

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<sup>182</sup> Pálsson (2002).

<sup>183</sup> Surely there are many reasons for the delay of HSD the project. Possibly it was too expensive for the purpose and the other two served the research well enough.

data's sensitive nature and because it originates from the confidential setting of the doctor-patient relationship. It was argued that presumed consent would go against one of the most basic principles of medical research: to respect individual autonomy with voluntary informed consent.<sup>184</sup> Furthermore, it was argued that the information has been gathered for medical reasons only, and neither hospitals nor doctors were authorized to hand over this sensitive information to a third party. Therefore, many argued for informed consent for processing medical records into the HSD. Supporters of the project, on the other hand, argued that informed consent would be far too costly and cumbersome, making it impossible for the project to succeed. Also some argued that the wide support for the project among the general public, present in public surveys, and the wide support during the long and intensive debate on the issue, amounted to democratic consent.<sup>185</sup> To compensate for presumed consent the law stipulated for strict security standards. This development showed how social norms had to adjust to a new context and technology.

A second issue concerned a more fundamental question of informed consent in relation to databases generally. For informed and voluntary consent participants must be able to choose whether or not to take part, and be properly *informed* about the aim of the research or the purpose of their participation. This means that individuals give consent to participating in one specifically-defined research project, where risk and benefit can be explicitly explained and understood by the participants. When constructing the database complex, it was evident that it would be a tool for genetic and medical research in the future, and therefore it would be impossible, when collecting samples, to inform the participants as to what kinds of research

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<sup>184</sup> See Nuremberg Doctors' Code and the Declaration of Helsinki.

<sup>185</sup> See Guðmundsdóttir and Nordal (2007).



would be conducted or how the information might be used later. Therefore, talking about *informed* consent would be a misnomer.

This debate has raised the question whether we should abandon the requirement of informed consent for databases and biobanks or if some other options would be available.<sup>186</sup> This has consequences for privacy. The control model of privacy assumes that individuals choose whether they give away their personal information or not, and for what purpose. If informed consent is not possible it seems that privacy has not been respected. To meet these challenges different forms of consent have been introduced, such as broad consent, open consent, and dynamic consent.

*Broad consent* requires that participants are asked to consent to the use of samples and data within a biobank at the time of collection rather than to a specific project. This procedure has become the recruitment standard for biobanks because it is argued that in the case of biobanks there is low risk of harm from future biomedical research. It has been argued that if the participants voluntarily accept this level of risk, and if there is also a mechanism of withdrawal available, broad consent is ethically acceptable.<sup>187</sup> For privacy this means that individuals agree to relinquish the control of their personal data and allow for future use.

*Open consent* has been introduced to meet challenges created by genome sequencing. With genome sequencing absolute privacy of data within biobanks cannot be promised any longer.<sup>188</sup> This means that participants must be aware that “the data can be and likely will be accessed, shared and linked to other sets of information, and that full purpose and extent of further usage cannot be foreseen.”<sup>189</sup> By giving open consent individuals also realize that they

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<sup>186</sup> See discussion in Arnason (2004).

<sup>187</sup> Hanson et al. (2006).

<sup>188</sup> Lunshof et al. (2008) p. 406.

<sup>189</sup> Lunshof et al. (2008) p. 409.

are potentially identifiable and that their privacy cannot be guaranteed. It means that individuals consent to unrestricted re-disclosure of data originating from a confidential relationship. The leading moral principle behind open consent is veracity; people are informed about the fact that there is no way to conceal personal identification or control who will have access to the information. If privacy means having control of personal information or having restricted access to information, then people are giving up their privacy with open consent.

Finally some have introduced one more model of consent called *dynamic consent*.<sup>190</sup> This model uses information technology to involve participants and enable them to give consent to the use of their samples over a long period of time, instead of only at the beginning when research commences or a biobank is constructed. In such cases individual consent can be obtained from research participants on a continuous basis, and they can opt out if they are not satisfied with how the research develops. Hence the construction of the biobank is designed to engage individuals over time.<sup>191</sup>

The controversy over different kinds of consent in relation to biobanks is strongly related to the definition of privacy as individual control and personal autonomy. Development of information technology has made it difficult to keep to the older framework of informed consent and therefore the trend has been moving to a broad, open, or dynamic consent. However these consents are different in relation to privacy and especially the control model. One of the problems with the control model, as discussed in chapter 3, is its conflation with the condition of having privacy and the ability to control for instance space or information. In the case of open consent and broad consent, people accept handing over information and thus exercise control over the information, but at the same time they give up their privacy in

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<sup>190</sup> Kaye (2011).

<sup>191</sup> Kaye (2011).

relation to this information. This is especially true for open consent where people realize that the information may be identifiable and therefore not anonymous. Since the control model places the onus on the individuals, as having control over their personal information or giving it up, the recipient is free to use the information at will. According to this model there is no place for privacy protection once the information has been disclosed. Surely someone who endorses the control model may simply choose not to participate in the research, but that seems to be the only option: either to accept and disclose information or to decline any participation.

Dynamic consent gives an opportunity for more nuanced participation. There the individuals do not give their consent to disclose information only at the beginning; rather, their consent is an ongoing process. This is a form of dialogue between the participants and the biobank over a period of time, with the possibility of opting out in this process. Therefore we can say that dynamic consent addresses Inness' concern over individual control discussed in chapter 3, of how control does not only refer to initiating a situation, but also the ability to regulate the situation as it continues or end it if required.<sup>192</sup> This requirement has been met to some extent in the case of biobanks with being able to opt out, but it is not enough to have a possibility of opting out unless we are informed about the use of our samples. Dynamic consent is constructed in such a way as to enable individuals to follow the research and authorize the use of their data as the process progresses. The social model of privacy highlights how privacy is about sharing information where the obligations of those who handle the information are specified. Dynamic consent is a move into that direction although it still relies on the model of individual control. I will discuss dynamic consent further in chapter 5.

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<sup>192</sup> Inness (1992) p. 48-49.

The possibilities of storing, linking and processing different kinds of data are growing every day, with unforeseen consequences. This shows in effect the challenges that modern technology poses for basic ethical principles such as informed consent and privacy. Although individuals are able to give their consent to storing their personal information, their knowledge of the use and processing of this data will always be limited. Hence the ethical principle of consent and control has been forced to adapt to a new environment, and accept the fading possibility of consent and individual control in this context. We have seen that genetic databases challenge both the control model and the separation model, not only because of how technology works, but also because of the “nature” of genetic information and the question of how well we can distinguish between sensitive and non-sensitive personal information.

#### *4.3 Personal information and genetic databases*

Until recently the secrets of the genes have remained hidden to us. The merger of genetics and information technology made way for mapping and sequencing of the human genome. The possibility of decoding genetic information generated strong reactions: both excitement over the important development of human knowledge and clinical medicine, but also serious concerns about genetic discrimination which might alter our understanding of human nature in a profound way.<sup>193</sup> The phrase “genetic privacy” gained power and it was argued that genetic data is the most sensitive personal information. Subsequently genetic exceptionalism was defended, stating that “genetic information is uniquely powerful and uniquely personal and thus merits unique privacy protection”.<sup>194</sup>

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<sup>193</sup> Everett (2004).

<sup>194</sup> Cit. from Annas, Glantz and Roche in Murray (1997) p. 61.

#### 4.3.1 Genetic exceptionalism

In this section I will mainly examine four arguments supporting genetic exceptionalism and I will compare genetic information with genealogical information and ask if the former is really of a uniquely sensitive *kind*. As mentioned before the idea of distinguishing between sensitive and non-sensitive data relies on the perception of data as a piece of stuff that can be moved between different containers. Surely genetic information contains sensitive information on individuals, such as genetic make-up and likelihood of getting genetic diseases in the future, information that is closely linked with medical history.<sup>195</sup> But this is only partly true of genetic data since it also contains genetic information anyone can observe from seeing us, such as hair and skin color. Genetic information is, as Onora O’Neill puts it, neither intrinsically medical nor intrinsically intimate.<sup>196</sup> The question therefore arises how we should categorize genetic data, i.e. whether it should be defined both as sensitive and non-sensitive, or neither.

Another feature of genetic information that makes it highly sensitive, some argue, is that it constitutes “a future diary”. This means that our genetic makeup can reveal personal information and predict future health of individuals. Furthermore, this information that is coded in our DNA is gradually being decoded and having this information available may affect the individual’s view of himself and his prospects. Again, it is true that DNA information can reveal information relevant for future health conditions, but genetic data is not unique in this sense. We can make predictions from present lifestyle factors such as smoking or obesity about the future health of a person, though it is of course in many ways less accurate than genetic information.<sup>197</sup> Also we can make predictions based on information

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<sup>195</sup> Interesting discussion on genetic exceptionalism may be found in O’Neill (2002), Murray (1997) Everett (2004).

<sup>196</sup> O’Neill (2001).

<sup>197</sup> O’Neill (2001) p. 697.

about health factors of close relatives, which themselves might be public. So if someone's father and grandfather died early of heart attacks, we are in a good position to predict that they are also at a high risk of having a heart attack. We can therefore say that information that is not regarded as private or sensitive – information that we take no precautions in protecting – can reveal quite a lot about our future health, as can genetic data.<sup>198</sup>

Third, it has been pointed out that genetic information not only concerns the individual but reveals information on other family members as well. We are genetically related to our biological siblings and parents, and information on one family member may imply information on another. Identical twins, for instance, have similar genetic makeup. If one of them reveals genetic information, then she is in fact giving information on the other as well. This raises important questions: Do we need consent of both? What if there are disagreements? Genetic information is not the only personal information revealing familial details. This fact is often overlooked by privacy advocates. Revealing what a member of a big family has inherited from his parents may reveal personal information on the family's wealth that other members might have chosen to keep secret.

Fourth, it has been argued that genetic information gives us unique power to discriminate against individuals or groups. Most often the discussion in the literature is about the risk that employers and insurance companies will discriminate based on genetic information. But is genetic data unique in this sense? We have frightful historical examples of stigmatization of groups long before the discovery of DNA. And it is possible to make personal profiles with personal information gathered from the public sphere. We could take examples from Iceland, a nation where public records of families go far back and where many

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<sup>198</sup> Stefánsdóttir et al. (2013).

people take pride in knowing of relations between individuals.<sup>199</sup> These relations are, for instance, published in obituaries in the daily newspapers and books are published on families and family relations. All this public information is readily available and can reveal information on health conditions of individuals and families and as such this information is available to employers and insurance companies just as to anybody else.

#### *4.3.2 Genetic information and communication*

As we have seen, gathering information from the public sphere can give us quite a detailed profile of individuals or families, and this can result in stigmatization if misused. Hence, it does not only matter whether information exists in the public sphere or is kept private; what matters is how information is used and interpreted. This discussion manifests to what extent drawing the line between sensitive and non-sensitive information is problematic. This is in accordance with the criticism of Manson and O'Neill of the container model discussed earlier and their alternative agency model. What matters is the communication aspect, how people understand the information, and what the hearer may already know. Hence, whether information is sensitive or not depends on the context and how the information is used, rather than the content.<sup>200</sup> A little anecdote from elections in a small constituency in Iceland in the 1950s explicates nicely how context-dependent information can be. As is custom in elections in Iceland, absentee votes are counted separately. Shortly after the election the leader of one of the parties which got little support meets one of the voters. After a casual conversation the voter reveals that he was away on election day and voted as an absentee. "Oh, so you did not

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<sup>199</sup> The public interest in *The Book of Icelanders*, the genealogical database structured by DeCode, is a good example.

<sup>200</sup> Tavani (1999).

vote for us,” the leader replied. The other person was taken aback and asked, “How on earth do you know?” “We did not get any of the absentee votes,” he replied.

Bio samples contain complex information about the individual that can be classified as both sensitive and non-sensitive. This is problematic for the separation model which relies on the possibility of being able to restrict access to certain kinds of information. Furthermore it shows that we do not always have the control of information about ourselves that the privacy literature assumes. We are part of a web of relatives, both genetically and historically. Thus genealogical, genetic and medical information all apply not only to one particular individual, but also to his or her relatives. The control of this information is therefore shared with many.<sup>201</sup> We are also part of a social web that gives background to all kinds of interpretation. As I have already mentioned, lifestyle factors such as smoking and obesity may predict future health conditions, and social standing or class may reveal all kinds of personal information beyond our individual control.

If there is no essential difference between genealogical and genetic information in this respect, we must ask what implications this has for privacy protection. Should genetic information be treated like genealogical information with no privacy protection – or should we change the way we handle genealogical information? This question points to the problem we face when categorizing information in different containers, as private or public, sensitive or non-sensitive. At the time when the secrets of genes were still mysterious, genetic privacy had no place in the privacy literature. Now genetic data is regarded as highly important. At the same time we have seen how insurance companies can use genealogical information as well as

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<sup>201</sup> In addition to this criticism of genetic exceptionalism it has been argued that it promotes genetic determinism, Everett (2004). The emphasis on the genes and their unique power enhances rather than decreases the mystique over DNA and shows how our secrets are importantly written in our genes rather than in other factors.



genetic information to discriminate against individuals. What matters is therefore not whether the information is accessible to everyone, but how it is used, interpreted, and understood. Furthermore, public knowledge can change with changes in our society. In Hitler's Germany the list of Jews, kept by the Jewish community for its benefit and cohesion, became the ground for efficient gathering of them into concentration camps. Records that had been important in keeping a community together became death lists overnight.<sup>202</sup>

Our society and technology are constantly changing and our knowledge improving. This makes it hard to foresee the future use of information. As I will argue later, we should therefore focus on possible use and misuse of information rather than the content, and thus the agency model is more useful for this purpose. Genetic databases do not only pose a problem because people regard genetic information as highly sensitive; the fact that genetic information is stored and processed as computerized data generates new threats to privacy. Information technology provides a way for aggregating, processing and connecting enormous amounts of personal data – issues that I will now turn to.

#### *4.4 Data mining, group profiling and privacy in public*

Modern technological society collects personal information on citizens in many of their daily activities. It is impossible for individuals to keep track of information collected, to know where the databases are stored or who has access to them. In most cases our activities produce information being stored without our knowledge in banks, shops, computer servers, telephone companies, social institutions, health care services and education systems. Databases and monitoring of the public are not only challenging privacy and individual control of personal

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<sup>202</sup> A vivid description of how these lists were used in Hitler's Germany can be found in Arendt (1994).

information, but also transforming the public sphere. In this section, I will examine such technology, starting with data mining and group profiling and then turn to privacy in public.

#### *4.4.1 Technology*

One feature of computerized databases is that within them information is *greased* which means that it can travel easily between different databases or contexts; such information “moves like lightning and is hard to hold onto”.<sup>203</sup> We can now access information in seconds on the Internet from all over the world, and in many cases where individuals have published information on blogs they do not realize how fast such information can travel.<sup>204</sup> This affects the control model of privacy since people have almost no control over their computerized information.<sup>205</sup> The fact that information travels fast poses an interesting question regarding the possibilities of opting out of databases. In the bill on the HSD in Iceland the option was given to opt out anytime. However, once information is used for genetic research, a new database has been formed with new information and therefore it may be hard to trace the information. Given how easy it is for information to travel from one context to another, we can ask whether it is realistic that information can actually be withdrawn, or whether the use of the information can be traced. This new digital reality upsets our traditional understanding of databanks as containers of information; they should rather be seen as networks of information travelling across different spheres, connecting with new information and changing constantly.<sup>206</sup>

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<sup>203</sup> Moor (2004) p. 349.

<sup>204</sup> Solove (2007).

<sup>205</sup> Recent disclosure of the monitoring of e-mails and other computerized communication show this vividly.

<sup>206</sup> Kaye (2011).

It is a common view that an aggregation of information does not violate privacy if its parts, taken individually, do not.<sup>207</sup> *The Book of Icelanders* contains information which is publicly accessible, from books, public records or public memory. One can argue that since people have not objected to the publication of this information, they cannot possibly object to the aggregation of the information in computerized databases. Unlike information in the public sphere, information aggregated as computerized data can be shifted to a new context, and combined with new data, giving a fuller profile of individuals, their lifestyles and activities. When this occurs it gives rise to new information that was not available before. As Nissenbaum explains:

Through the powers of information technology we acquire the capability not only to collect and store vast amount of information, but to bring order to it, to manipulate it, and to draw meaningful inferences from it. By these actions we are able to inject shape and also value into a riot of formless data.<sup>208</sup>

In this environment all kinds of information can become relevant and we may not be able to foresee its usage. We would pause if we found out that our neighbour kept records of our whereabouts in public, our purchases and acquaintances, even though we did not try to hide such information or regard this information as secret. We would wonder about the motive for such surveillance. Also once the information has been gathered in this way we have new information consisted in the patterns. With computerized databases and surveillance technology in modern societies, the records may be kept on computers, and we tend to look at the technology in a neutral way. Unlike human memory, however, information in computerized databases is readily available, keeps better, is more reliable, but most

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<sup>207</sup> Nissenbaum (2001) p. 400.

<sup>208</sup> Nissenbaum (2001) p. 401.

importantly can be manipulated, as Nissenbaum points out, in unprecedented ways. In the past manipulating and shaping such files would have been enormously labour-intensive. Information technology, on the other hand, gives rise to data mining where it is possible to go through enormous data and give it a new shape.

The Icelandic Database Complex is an example of a set of databases where various information can be connected for important biomedical research, and private or sensitive information can be connected to public information, shifting information from one context to another. In this environment we can hardly expect much control of our personal information. Moreover, the technical environment blurs the distinction between the public and the private, or between sensitive and non-sensitive information, as we saw in the case of genetic and genealogical information, showing the importance of context rather than the nature of information in this matter.<sup>209</sup>

Many have argued that privacy and security have been conflated in the discussion of genetic databases. The Icelandic Database Complex required high security standards and for many that substituted for informed consent and personal control. It was discussed whether information on individuals should be coded or anonymized, who should have access to the data and on what terms. Furthermore it was pointed out that the data was owned by a private company, and although the databases were constructed for certain defined purposes such as health research, the owners could change their minds. If privacy means having individual control of information then security standards cannot replace privacy.

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<sup>209</sup> Taviani (1999).

#### 4.4.2 KDD and group profiling

With the development of informational computerized technology, we are seeing new possibilities of what has been called *Knowledge Discovery in Databases* (KDD). KDD is usually divided into three phases: the *warehouse phase* where the data is collected, enriched, checked and coded; the *data mining phase* where the data is analyzed; and finally the *interpretation phase*.<sup>210</sup> Data mining is a particular step in the process of KDD, namely to discover patterns of group behaviour though recently the term has been used more broadly.<sup>211</sup> Data mining is used for various different purposes, for instance marketing, forensic research or genetic research, creating powerful group profiles. Such group profiling is not entirely new, but the computerized data makes it possible to go through enormous data in a short while and to discover “hitherto unnoticed relationships between characteristics and features of persons, created by KDD”.<sup>212</sup> The data mining tools contributed greatly to the Human Genome Project and have created novel opportunities for genetic research, since it makes it possible to “sift through the DNA of large populations [...] in an effort to identify the underlying genetic causes of diseases.”<sup>213</sup> Instead of observing connections between characteristics as epidemiological researchers did in the past, with the data mining technique different databases, or data, can be compared in a short time, creating new profiles of people or groups.

And it is precisely the possibility of group profiling that is causing more concern. We all belong to many groups, whether being female, a car owner or a smoker. Being a member of a group can be part of our identity; we are fully aware of such as being female or a medical doctor. There is no need for data mining to associate us with such groups. However, with data

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<sup>210</sup> Vedder (2001) p. 401.

<sup>211</sup> Taviani (1999).

<sup>212</sup> Vedder (2001) p. 407.

<sup>213</sup> Tavani (2004) p. 21.

mining tools it is possible to suggest new facts about individuals. For instance, it might reveal a group that both has colon cancer and drives a red car.<sup>214</sup> Furthermore, group profiling can identify us as belonging to a group based purely on probability, such as of developing a disease or developing a certain behaviour pattern, for instance being more likely to divorce your spouse if you own a special kind of car.

Vedder argues that the social implications of group profiling may be that individuals will be regarded less as individuals, and more as belonging to a group or groups. This may give rise to unfair discrimination and stigmatization, especially if the group profiling is based on sensitive personal information. To illustrate this point further Vedder distinguishes between distributive and non-distributive profiles. The former identifies some “properties to a group of persons in such a way that these properties are actually and unconditionally manifested by all the members of that group”.<sup>215</sup> Non-distributive profiles only state probabilities or averages, such as having a higher risk of getting liver cancer because of living in certain parts of the city. Such facts will not be true of every individual member of the group, and we won’t know which members of the group it is true of. That is, we often won’t have any way of deducing claims about individuals from claims about groups. In such a case the person may not have the knowledge of or conceive of himself as belonging to this group. According to the control model information on groups would not count as private information and hence group profiles are not protected by privacy.

Nevertheless some have argued that it should be protected in cases where information in the profile is of a sensitive nature or gives rise to prejudice or stigmatization. Although in such

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<sup>214</sup> Tavani (2004) p. 22.

<sup>215</sup> Vedder (2001) p. 407.

cases simple probability does not state a fact about the individual, he may be “judged and treated on the basis of his, coincidentally, belonging to the “wrong” category of persons.<sup>216</sup>

Hence it has been argued that KDD and group profiling generates new threats for privacy protection, threats that current legal understandings of privacy do not manage to address. Since the group profiling processes information on groups but not individuals, traditional understanding of privacy as protecting individual control of personal information does not apply. For instance, the European Data-protection directive only applies to personal data as identifiable to a certain individual, but does not attend to security of groups even though being wrongly associated with a group can have serious effects for individuals. Still, as Vedder argues, group profiles are often used as if they are personal data and can be a ground for stigmatization. This is particularly unfair in the case of non-distributive profiles.

To meet the challenges of individual privacy within groups, Vedder introduces the notion of *categorical privacy*. Like individual privacy categorical privacy is meant to respect individuals rather than groups “but draws attention to the attribution of generalized properties to members of groups, which, however, may result in the same effects as the attribution of particularized properties to individuals as such.”<sup>217</sup> As with the traditional notion of individual privacy it relates to data that has:

1) originally been taken from the personal sphere of individuals but which after aggregation and processing is no longer accompanied by identifiers of individual natural persons, but, instead, by identifiers of groups of persons; and 2) when attached to identifiers of groups and when disclosed the information is apt to carry with it the same kind of negative consequences for the member of the group as it would for an individual person if the information were accompanied by identifiers of that individual.<sup>218</sup>

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<sup>216</sup> Vedder (2001) p. 407.

<sup>217</sup> Vedder (2001) p. 409.

<sup>218</sup> Vedder (2001) p. 409.

From this we see that categorial privacy does refer to individuals within a group but not to privacy of groups. The idea of individual privacy is broadened to categorial privacy to encompass individuals within groups, and the concept draws attention to the fact that general information about groups can be just as discriminatory as information about individuals. Still, there is no possibility of the individual controlling his or her personal information or the attributes that may be associated with him or her. Therefore Vedder argues that the only way to respect categorial privacy is to set limits to the ways in which such profiles may be used: “The only way to protect individuals against the possible negative consequences of the use of the profiles based on personal information in the broad sense lies in careful assessment of the ways in which the profiles are in fact used and can be used”.<sup>219</sup> This indicates that legislation is needed to give a framework for use of personal information and group profiles.

Vedder’s conclusion — that assessment must rely on how profiles can be used — is important. Nevertheless we see that Vedder relies on the distinction between sensitive and non-sensitive information, or information “taken from the private sphere”. I have, however, argued that “public” information such as genealogical information can, in certain contexts, be harmful to individuals or used for stigmatization. As has been mentioned data mining technology can be applied to genetic information stored in genetic databases. This issue was discussed in the case of the Icelandic project, since it gave a unique opportunity to construct group profiles on an entire population and estimate risks for getting particular diseases. In the future we can also see that more and more information will be connected together, such as on financial and social status, making extensive group profiles possible.

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<sup>219</sup> Vedder (2001) p. 410.



So far we have seen how information technology creates new challenges for individual privacy, both with possibilities of manipulating enormous personal data, and data mining and group profiling. Information technology does, however, not only challenge privacy for individuals generating from the private sphere but is also changing the public in profound ways.

#### *4.4.3 Privacy in public*

The public sphere is seen as open and accessible to everyone. Moreover, when we are acting in the public sphere we give away personal information freely. When we walk on public streets or buy in public shops, those around us can see what we do and how we behave, what we are wearing, what we are buying and so on. This is opposite to the sphere of restricted access, protected by the separation model, and we are giving away our control of personal information. More accurately, we are revealing to others all kinds of information without giving it much thought. According to this standard view of the public, a person who complains of privacy loss in public has misunderstood something essential about the public sphere.<sup>220</sup> Hence, for many it is paradoxical to claim privacy in public.

With recent technology development this simple description of the public sphere is changing dramatically.<sup>221</sup> Our movements and actions in the public space are not only open for others to see and observe; they may possibly be monitored, stored and kept in modern databanks. Also broadcasting on television or on the Internet makes what happens not only accessible to those present in the public at the time, but to viewers everywhere, making the publicity more concentrated and intensified. The monitoring of the public is affecting our sense of anonymity in public. It is a truism that in crowded streets we are seen by many but

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<sup>220</sup> See earlier discussion.

<sup>221</sup> Reiman (2004), Friedman (2000), Nissenbaum (2010), Nissenbaum (1998).

observed by none. This is also changing. Cities have monitors on their downtown streets; shopping behaviour is tracked through our credit cards; the local video store or Netflix has a list of our movie preferences; our travels on the internet are listed somewhere in the cyber world and so on. How does this information violate our privacy? After all, we know we are observed in public places and, moreover, information about our walking in the streets is non-sensitive anyway.

It is true that we give this information freely; we pay with credit cards, walk in the streets, and so on. And it is true that our daily habits are not categorized as highly sensitive. Who cares what cheese I buy and whether I buy meat once or three times a week? Nevertheless we object. The problem we face is that this information is kept and can be used in new and different contexts. Along with information on our health, finances and so on, it is possible to build a profile of us and analyze our behaviour in detail. Instead of being seen by many and observed by none in the public sphere, as has been the case, we may now be scrutinized by some, as our data is recorded and stored and may be used in the future in ways we cannot now imagine. In this sense, information technology is transforming our public sphere. And this transformation has given us good grounds for privacy concerns in the public. Therefore, privacy concerns are not only directed at information “originally taken from the private sphere” as Vedder has in mind when introducing categorial privacy, but must also take into account personal information from the public sphere as well.

Not only is the public being transformed by the technology but a new type of public sphere is being constructed on the Internet. When we move in the open public we are doing so as embodied beings, seeing others and being seen by others. The Internet is a new sphere of human interaction profoundly different from what we have known so far. When we browse on

the Internet we are not there as embodied beings: we do not see others and they do not see us; we can hide our identity. Still, we leave traces wherever we go on the Internet which can be tracked down and manipulated in many different ways. Amazon keeps records of our searches and purchases and is able to recommend further options. It has even been shown that the information collected by search engines can be used to isolate individuals in some cases.<sup>222</sup> Furthermore people often treat the Internet as a private sphere or at least as not completely public. In his book *The Future of Reputation* Solove describes many examples of how people treat their personal blogs almost like a personal diary or a personal letter, without realizing the easy access others have to their writings or photos. This has in some cases had disastrous consequences for individuals who have, without realizing it, been exposed on the Internet and their privacy seriously violated.<sup>223</sup>

The 'bank' or 'warehouse' metaphor used for databases suggests that information is kept in boxes or stored like paper files in warehouses. According to the container model, we move information from one context to another, from private to public. As we have seen, information technology challenges these views and metaphors. Rather we have networks, where information, travelling at lightning speed, connects with new information and is constantly changing, communicated and interpreted.

One thing is for sure: information technology is disrupting traditional categories and social norms of communication, as well as our understanding of information and how it is communicated between people. Our traditional norms do not apply in this new social reality and new norms are in the making. Furthermore the new technology is disrupting the traditional ways of thinking about privacy and the ways in which personal privacy can be protected. In

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<sup>222</sup> Barbaro and Zeller (2006).

<sup>223</sup> Solove (2007).

some cases we are not even treated as individuals but as part of a group. In the computerized world there is no place for restricted access, which means that separation as understood in the separation model is simply not possible. We have also seen that control of our personal information seems hard to reach. Still, some have argued that information technology offers the potential to empower individuals in protecting their privacy. In the next and final section of this chapter, I will examine such arguments.

#### *4.5 Information technology: a tool to empower individuals*

Privacy, understood as control of personal information, focuses on empowering people to protect their information. This model requires that we leave as much as possible to individuals to decide: e.g. who has access to their personal information. The problem is, as we have seen, that in a world of modern information technology individual control or consent can be very limited indeed. Once we have handed over our credit card number at the store, we do not know what will happen to information gathered: whether the store will keep our name on their list, whether they keep track of our purchase, or if they will simply delete it right away. With further development of technology, we cannot even imagine how it might be used in the future.

An advocate of privacy and individual autonomy might argue that although we have little control over our personal information, we have some control, and we should try to preserve as much control as possible.<sup>224</sup> It has also been argued that technology can give individuals more tools for control, or empower them in protecting their privacy. Within modern technology there are great possibilities of informing people of different uses of information, hence individual control can be gained in many ways. When these possibilities

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<sup>224</sup> DeCew (2000).

are exhausted, we simply might have to live with the fact that our personal information cannot be controlled or protected any further.

DeCew discusses the advances of caller ID and dynamic negotiation to ensure the control of individuals over their personal information.<sup>225</sup> In this system, telephone callers are identified by name and phone number to whomever they call. In addition, it is possible to have dynamic negotiation between the caller and the receiver. In such cases phones would be set up to refuse calls where the caller is anonymous. Instead the callers would get a notification and an opportunity to make themselves identifiable and continue with the call. In this system the callers control when they wish to give out their numbers if the calls are important enough to surrender their anonymity. Also the call recipient can screen his or her calls and deny anonymous calls.

DeCew has argued that the main principles of dynamic negotiation can be adopted for the use and storage of medical records. The main attraction, according to DeCew, is that it would put priority on privacy in this field. Another factor of this system is the negotiation that needs to take place between patients and those who want to access their medical information. The user of information would have to inform the patient both of the use and the need to access to the information, or as DeCew states, it would require “health care providers and secondary users to have an ongoing conversation or meaningful dialogue with patients before gaining access to their data.[...] This is to educate patients so that they understand the benefits of the release of their data”.<sup>226</sup> Furthermore, this system would also give the patients themselves access to their medical records just as to their financial statements in electronic

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<sup>225</sup> DeCew (2000) and DeCew (1997).

<sup>226</sup> DeCew (2000) p. 230.

banking. The overall aim of this system is to require more active participation of the patient, and enable him or her to control who will get access to his or her records and who will not.

There are many problems with this system, as DeCew acknowledges, and it could not be applied in a simple or straightforward way.<sup>227</sup> Adopting such a system for medical records is not easy; it is both time-consuming and costly. I want to focus on different issues than the ones DeCew raises and will discuss four separate issues. First, this system seems to raise questions about conflicting privacy interests. Second, it is not clear if people would actually want to be asked for access every time their medical information is used. Third, this system does not take into consideration the fact that the parties involved are not on equal footing. Fourth, the system does not address the fact that medical information is not only individual information but familial.<sup>228</sup>

First, if we want to call someone, we want to talk to her in person; when we want to look at medical information, we only need to read the files about that person but not necessarily have direct access to her. The dynamic negotiation system requires not only access to the files, but also access to the person herself. Therefore, this system raises new privacy concerns, namely the issue of intrusion. The caller ID gives a person the possibility of controlling access to herself, by screening telephone calls. The dynamic negotiation system would require more access to the person and more intrusion than simply reading files. Here we have therefore a tension between privacy as limited access to ourselves and privacy as control over data.

DeCew might reply to this point saying that this would give us control over our medical information, and we would not mind more access to us to gain that control. What matters here is also whether people would have the option of opting out; that is, not take part in this

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<sup>227</sup> DeCew (2000) p. 226.

<sup>228</sup> Nordal (2007).

dynamic negotiation but simply allow the use. Then people would voluntarily waive their privacy and give up their control. A reason to do so might for instance be to protect other privacy interests, e.g. privacy as non-intrusion. Moreover there are further reasons to believe that some people might, in fact, mind the intrusion included in this system and that brings me to the second criticism. Caller ID is a system set up to control direct access to the person by screening telephone calls. The picture is much more complex in the case of data “out there”. Our medical records or genetic data are stored within the medical system, or within corporations or institutions doing medical research. Although these records might be highly valuable for medical research or managing public health care, individuals do not normally need access to them on a daily basis. In this respect, medical records are unlike our financial data or electronic banking. We need to have access to our finances almost daily, but once we are out of a hospital or a doctor’s office we might just want to forget the experience. We might never want to read those files, and certainly not want to be reminded regularly of our past illnesses or drug use, and such reminders may count as intrusive. Our medical records are only important to us when we are sick, or when a medical professional needs it.<sup>229</sup>

The third issue I want to take up stems from the citation from DeCew above. This dynamic negotiation system requires that patients are “educated” on the benefits of releasing data. This indicates that the negotiating parties are not on an equal ground to begin with, for at least two reasons. On the one hand, the user of the information is most likely more knowledgeable and needs to inform or “educate” the patient. On the other hand, it is most likely that the information user has more power than the patient in the negotiation process, not only because of better knowledge, but also because he or she represents health care the patient

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<sup>229</sup> Apart from physical privacy and informational privacy Friedman talks about attentional privacy. Friedman (2000) p. 187.

needs or an insurance company the patient depends on. The patient might feel the need to cooperate with the information user rather than deny access to information. Furthermore, the patient might not even wish to become knowledgeable on these issues which might both require time and effort on his behalf.<sup>230</sup> We might argue that asking people for permission every time the data is used might be a way to make them responsible for the use of the data, a responsibility which correctly should lie with the researcher. The system of dynamic negotiation is portrayed as a system between two individuals, but this overlooks the fact that doctors and researchers are part of complex institutions, with practices, ethical principles and guidelines. It is with such institutions that individuals are sharing their medical or genetic information.

Fourth, it has been pointed out that our medical information not only concerns the individual but reveals information on other family members as well. Someone might share publicly their particular diagnosis known to run in families. Such information might therefore reveal information on others who might not want to have it publicly known.

This shows that direct control of our medical information with the help of dynamic negotiation is problematic. The advantage of this system is that it recognizes that personal information is about sharing information, but it rests on the notion of individual control. Therefore this system overlooks the conflicting privacy interests, the complexity of institutions, and the social norms at play. Furthermore individuals can still waive their privacy and hence any privacy protection. These issues will be taken up in the next chapter.

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<sup>230</sup> Some of these issues are similar to the ones that arise in the context of informed consent in bioethics and are discussed by DeCew.



#### *4.6 Conclusions*

Plans to construct health databases and biobanks generated much controversy some years ago, both because of the technological possibilities such as data mining and profiling, and also because of the possibility of decoding what seemed to be the innermost human secrets. Hence, such projects challenged traditional definitions of privacy – both the emphasis on individual control and for demarcating between sensitive and non-sensitive information.

This chapter began with a general discussion of personal information and introduced two models which show different understandings of information: the container model and the agency model. The container model depicts information as a piece of stuff that we can convey from one place to another, that we can keep hidden or reveal. This model coincides with the perception that we can categorize information either as sensitive or not, as private or public, and that we can control who has access to information or whether information is in one sphere or the other. In preceding chapters I have argued that the public-private distinction does not give groundings for our understanding of privacy and that privacy does not belong only to the private sphere. The examination of the Iceland's health data project, in this chapter, gave one more reason for rejecting such categorization. Genetic information, often described as most sensitive, turns out to be both sensitive and not sensitive, and genealogical information that is accessible to the public can be a cause of discrimination and harm. Also, individual control of such sensitive information is not readily available.

The container model is challenged further with the development of information technology – with the possibility of shifting information from one context to another, making surveillance and monitoring effortless, allowing for all kinds of manipulation, data mining and group profiling. This makes individual control difficult and in some cases next to impossible. In the case of group profiling, it is even debatable whether information should be treated as

personal information at all. One appeal of the container model is that it matches the metaphors we often use, such as “banks” or “warehouses”, when talking about information in the digital world. However, these metaphors do not capture correctly the flow of information and fluidity in information networks.

The agency model gives a more realistic explanation of how information is shared between individuals and how information flows in networks. There the focus is on the communication aspect of information, and how interpretation of personal information is susceptible to norms and background knowledge of the receiver. Genetic samples as such do not tell anything; such samples must be decoded and interpreted to have some meaning, and even then it depends on the understanding of the one who reads the information or his or her background knowledge. Hence, the agency model describes information in relation to communication and interpretation rather than as something fixed that is moved from one place to another. This model directs attention to the social context and background norms when evaluating information. Thus the model focuses on context rather than content. As it turns out, this model better meets the challenges of information technology. It captures the fluidity of information – how it travels both between individuals and in networks.

If the container model and the traditional understandings of privacy as given in the control model and the separation model do not address the challenges of information technology, we must look for different ways of protecting privacy. I have already discussed the social model of privacy and argued that instead of looking at privacy as an individual capacity we need to direct our attention to the protection of privacy. In the next chapter I will introduce a framework of obligations to meet these challenges. This is Onora O’Neill’s

account of obligations and trustworthy institutions, and I will argue that it can be a ground for re-thinking the right to privacy.

## Chapter 5: Privacy, Community, and Trust

In previous chapters I have examined the two prevailing models of privacy: the separation model and the control model. Both these models depend on the assumption that there is a sphere of non-interference and hence privacy seems to be best protected as a negative right. Understanding privacy as a claim against others and its connection to related concepts such as autonomy, trespass and invasion, intuitively directs our attention to the language of rights – specifically, to rights of non-interference that pertain to all human beings.<sup>231</sup> Furthermore, the control model is grounded in the liberal notion of autonomy or the idea of the individual as “the self-aware project maker” who is “a distinct centre of self-consciousness, having the notion of himself as a distinct entity alongside other similar entities”.<sup>232</sup> Therefore it is no surprise that within the literature we find a legion of papers addressing privacy as a right.<sup>233</sup>

However, in this thesis I have argued against these two models and emphasized the social aspect of privacy. I have focused on how privacy interests are deeply entrenched in social norms and how privacy must be understood as a value in relation to other people. As we saw in the last chapter, information technology introduces special challenges to the two models of privacy, where it was demonstrated how little control individuals have over personal information and how many privacy challenges there are within the public sphere, in the technological context. Instead, individuals are dependent on social practices and how others use information they have access to. For these reasons it seems the framework of

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<sup>231</sup> Paul, Miller, Paul (2000) p. viii, Epstein (2000) p. 5.

<sup>232</sup> Benn and Gaus (1983) p. 33.

<sup>233</sup> Paul, Miller, Paul (2000), Warren and Brandeis (1890), Davis (2009) Thomson (1975).

negative rights is not going to do the job to provide protection for privacy – or the framework is at best very limited.

If negative rights do not provide an appropriate framework for protecting privacy we must ask what other options are available. I will argue that we need to approach the problem in a different way that both acknowledges social practices and includes social institutions. In order to do so I will, in the last part of this chapter, introduce a broader framework that I believe captures the concerns and interests associated with privacy, and is more sensitive to social structure and practices than the framework of rights. This framework relies on obligations and trust rather than rights and duties.

The chapter begins with a discussion of rights and an evaluation of privacy as a negative right. According to many thinkers, rights of non-interference are the only genuine human rights.<sup>234</sup> However, I will argue that the framework of rights fails to deal with challenges of information technology. This is primarily due to the fact that the rights framework is not sensitive to social norms and social institutions. Also I will argue that rights do not tackle all sorts of privacy concerns in more informal settings, which are still normatively important. But rights are more than negative rights or rights of non-interference, and if negative rights are not helpful in protecting privacy it is natural to turn to positive rights, even though many proponents of rights theories criticize positive rights for being too burdensome.

In the second section I will discuss criticism of negative rights presented by Henry Shue and Onora O’Neill. Shue argues persuasively that for all rights to have any substance, they need some social structure or institutions. Therefore, he argues that the distinction between negative and positive rights is not well-founded. Instead, he argues that we need to put more

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<sup>234</sup> Orend (2002) p. 32.

focus on obligations and which institutions are necessary to secure any basic right. Shue's analysis is important for understanding privacy because he directs the focus towards the social structure or institutions needed for enjoying any rights. Another writer who focuses on obligations is Onora O'Neill. She not only argues that we should start with obligations but she also, drawing on and developing Kant's theory of obligations, introduces a rich understanding of obligations both perfect and imperfect, where obligations are primarily a relational concept. I will use O'Neill's framework later in the chapter to discuss how privacy should be analyzed in relation to obligations rather than rights. O'Neill's theory brings together obligations and institution building, or trustworthy institutions, the structures that are needed to have privacy when we share with others.

Privacy has several times been associated with trust and trustworthiness. Some have argued that privacy can only be enjoyed in the private sphere, or in a trusted environment. However, trust is also needed and is important in the public, as Trudy Govier's examination of social trust shows. In the third section, I will explore further the concept of trust and especially the notion of social trust in relation to privacy. It turns out that these relations depend on what notion of privacy we accept. If we see privacy primarily as a right of non-interference or a claim to be away from others, then it might be justifiable to say that privacy undermines community which relies on mutual respect and trust. If, on the other hand, we rely on privacy in relation to obligations, this account of privacy directs us naturally towards others, the community, and trust.

In the fourth and final section I will sketch a framework for protecting privacy as a social concept. This framework, which is based on O'Neill's interpretation of perfect and imperfect obligations, is able to pick up various privacy interests. Furthermore it outlines what

is needed to build trustworthy institutions to protect privacy. The social model of privacy presented here is a very different way of thinking about privacy than is represented in privacy as a right of non-interference. In my view this is a more realistic way of thinking about privacy than the control model or the separation model offer, and helps us in clarifying different interests associated with privacy.

### *5.1 The structure of rights and the right to privacy*

In this section I will discuss some general issues of rights, such as the logical connection between rights and duties, the distinction between negative and positive rights, and how rights are universal claims of individuals. Surely, if privacy could be persuasively applied to the framework of rights, it would give privacy a strong moral force. However, I will argue that the framework of rights is too explicit or rigid a tool for privacy, lacking the nuances and flexibility needed to capture the social aspect of privacy. Instead of relying on the rights model, I later propose perfect and imperfect obligations as a broader framework to deal with privacy concerns.

#### *5.1.1 The structure of rights*

Rights have been defined as a “justified claim on someone, or on some institution, for something which one is owed.”<sup>235</sup> When we claim that a person has a right to something we mean that he or she is entitled to a certain kind of treatment or respect from other people or institutions; this respect is not given out of kindness or generosity.<sup>236</sup> Hence rights are most naturally thought of as individualistic in the sense of being entitlements of individuals. The substance of the right must be important enough to be justified in imposing duties on others.

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<sup>235</sup> Orend (2002) p. 17.

<sup>236</sup> Feinberg (1973) p. 58.

Rights are logically connected to duties. If someone has a right to something, it means that someone else has a duty or an obligation to honour this right.<sup>237</sup> To describe these duties that arise from rights a distinction has been made between negative and positive rights and corresponding duties.<sup>238</sup> Negative rights are rights of non-interference, which means that a duty corresponding to a negative right is a duty to refrain from doing something. Freedom is negative in this sense; as long as others do not obstruct us, we have freedom to do what we like. Furthermore this is a universal requirement on others to stay away and refrain from obstructing people. Positive rights, on the other hand, generate duties on others to act positively towards us or to provide something. These rights are often called welfare rights or rights to “goods and services”.<sup>239</sup> To have a right to education is a positive right in this sense because it requires a duty on someone to provide education. Positive rights are viewed as burdensome and costly but it is both reasonable and affordable to require non-interference. Therefore it has been argued that negative rights are the only genuine human rights.

### *5.1.2 Privacy as a negative right*

Following the publication of Warren and Brandeis’ influential paper on the right to privacy, various legal cases appealed to this right in US courts, and gradually it has been established as a constitutional right. In spite of substantial criticism of privacy as a right, the awareness of the right to privacy has spread to other Western countries. Now, more than a century after this discussion was launched, the right to privacy has found its way into the *European Declaration of Human Rights*, and from there into constitutions of many European countries. Privacy is

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<sup>237</sup> Waldron (1984) p. 2, Feinberg (1973) p. 61-64.

<sup>238</sup> Berlin (1969).

<sup>239</sup> O’Neill uses “goods and services” instead of welfare rights. See for instance O’Neill (2005) p. 427.



therefore not only seen as a legal right, but a basic human right, pertaining to all human beings. The right to privacy is usually described as a right of non-interference.

Why is this so? First of all, Warren and Brandeis originally understood privacy as being let alone, associating it with the sphere of non-interference.<sup>240</sup> Even though their definition has been dismissed for being both too broad and too narrow, privacy continues to be seen as a value of the private sphere.<sup>241</sup> As we saw in chapter 2, this is both true of the separation model and the control model. The separation model is about securing a space where we are away from others; and according to the control model enjoying privacy means that we are able to keep others away from our private space unless we invite them to share it with us. Likewise, individuals should be able to determine for themselves to what extent information is communicated to others and/or accessible to others. Therefore, one important aspect of privacy protection is to protect individuals against intrusion, or secure a sphere where we can be away from others. This understanding of privacy emanates from the classical liberal tradition, such as tort and contract.<sup>242</sup> One privacy advocate, Richard A. Epstein, argues that the right to privacy can best be understood in relation to the classical liberal framework that stresses private property, freedom of expression and freedom of contract, with limited government on one side and the redistributivist state on the other.<sup>243</sup>

Second, applying the framework of negative rights to privacy gives privacy a normative foundation. Negative rights that only require that we refrain from acting, or not intrude, are generally seen as universal. Positive rights are, however, more complex, not only because they require that something is provided by the duty-bearer, but also because it is in many cases not

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<sup>240</sup> Warren and Brandeis (1890) p. 195.

<sup>241</sup> See for instance Thomson (1975).

<sup>242</sup> Epstein (2000) p. 5.

<sup>243</sup> Epstein (2000).

clear who should act or what should be done. However, as will be discussed in the next section, the distinction between negative and positive rights is highly problematic.

Third, rights have gained prominence in modern moral philosophy as being the only sufficient grounds for moral interests. Therefore, if privacy is representing an important moral interest we must be able to phrase it as a moral right. Furthermore, these rights theorists argue that all other theories to ground moral interests have failed or are too messy. As I will argue in this chapter, unfortunately, at least for rights theorists, we need a broader framework to meet privacy interests.

Although privacy is often placed within the conceptual framework of liberal rights or rights of non-interference, there has been a deep disagreement within the literature on privacy on whether there is a moral right to privacy and what would ground such a right.<sup>244</sup> There are several reasons why some scepticism may be justified. First, the concept of privacy is regarded as unclear. Judith Jarvis Thomson famously declared in her paper “The Right to Privacy” that “perhaps the most striking thing about the right to privacy is that nobody seems to have any very clear idea what it is”.<sup>245</sup> Obviously it is unfortunate that a right enforced by the law is conceptually unclear. Not only did Thomson criticize the conceptual vagueness of privacy, but she also argued that the right to privacy was not required in the first place since its interests were protected by other basic rights, such as the right to property, liberty, and the right over the person.<sup>246</sup> According to Thomson the right to privacy is derivative and it is a cluster of rights which intersects with different other such clusters. There is nothing specifically in the privacy cluster that is not also in other clusters; that is to say, “there is no need to find that-which-is-in-common to all rights in the right to privacy cluster and no need to settle disputes

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<sup>244</sup> Davis (2009) p. 450.

<sup>245</sup> Thomson (1975) p. 295.

<sup>246</sup> See also Davis (1959) cited in Thomson’s paper.

about its boundaries.”<sup>247</sup> Thomson’s link between the right to privacy and the right to property suggests that she has in mind the control model of privacy: we should be able to control our body and personal information similarly to the way we control our property. Since Thomson argues that privacy can be reduced to some other rights, her view has often been called a reductive view of privacy, and has been both discussed extensively and highly criticized.<sup>248</sup>

Second, rights apply to individuals but privacy concerns can be importantly shared between individuals. As I argued in the last chapter, some personal information, such as health and genetic information, is not only about a particular individual, but also about relatives or even groups. This introduces many profound problems for protecting privacy. If a family member wants to share information about genetic make-up within a biobank, he might be violating a right of another member of the family who wants to keep it a secret. Furthermore, when others are at risk, for instance because of HIV infection or a threat of contagious diseases, there may be good justifications why the right to privacy should be outweighed. For this reason Weinreb argues that to decide if individuals are justified in keeping their personal information, such as health information, secret or not, we need to consider different situations and contexts. Therefore, he argues that informational privacy is best grounded on utilitarian considerations.<sup>249</sup>

Third, the framework of negative rights misses the relational aspect of privacy and how privacy is grounded in social contexts. This can be illustrated by the doctor-patient relationship. Often the confidential duty and the professional relationship are seen as resting on a contract between the doctor and the patient.<sup>250</sup> Then the contract defines the rights and

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<sup>247</sup> Thomson (1975) p. 313.

<sup>248</sup> Rössler (2005) p. 67.

<sup>249</sup> Weinreb (2000).

<sup>250</sup> Epstein (2000) p. 20-21. See also discussion of the contract model in Koehn (1994), chapter 3.

duties in this relationship. However, the relationship between a patient and a doctor must be understood against a complex institution and structure, which define what is appropriate for doctors to do in different situations, such as the duty of confidentiality on behalf of doctors and the expectations patients can have in this respect. Therefore, the doctor-patient relationship is not best described as a contract; the contract model misses important aspects of this relationship.

To explore further the limitation of seeing privacy as a right of non-interference, I want to discuss an interesting case from Thomson's paper.<sup>251</sup> Her example nicely draws attention to the difficulty with separating violation of privacy from bad manners. More importantly, however, it shows how privacy concerns are grounded in social structure and must be sensitive to different contexts:

Suppose that my husband and I are having a fight, shouting at each other as loud as we can; and suppose that we have not thought to close the windows, so that we can easily be heard from the street outside. It seems to me that anyone who stops to listen violates no right of ours; stopping to listen is at worst bad, not nice, not done by the best people. But now suppose, by contrast, that we are having a quiet fight, behind closed windows, and cannot be heard by the normal person who passes by; and suppose that someone across the street trains an amplifier on our house by means of which he can hear what we say; and suppose that he does this in order to hear what we say. It seems to me that anyone who does this does violate a right of ours, the right to privacy I should think.<sup>252</sup>

As Thomson points out, there is an intuitive difference between the two cases. We can say that the couple has a right to privacy in their home and no one should eavesdrop on

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<sup>251</sup> Thomson (1975).

<sup>252</sup> Thomson (1975) p. 296.

conversations or fights there: we have a right to privacy at our home and against surveillance of any kind. If they keep the windows shut and the passer-by has an amplifier to hear what is going on, that person seems, therefore, to be violating the right of privacy. However, if the couple carelessly leaves a window open, making it inevitable for a passer-by to hear what is going on, they seem to have *waived* their rights to privacy. And the person who stops and listens is at most showing bad manners: it's "not done by the best people".

There are many things worth exploring in this example. Why, exactly, do we think that privacy is violated when the amplifier is used but not when the window is left open? Does it have to do with where it takes place? Does it have to do with the relationship between the couple fighting? Does the content of the fight – what is said – matter? Or does it have to do with the combination of all these features? Since Thomson argues that the couple has waived their right to privacy by leaving the windows open it seems that the critical thing is intrusion into the privacy space.

Let's suppose that the fight took place on the street in front of the house or in a public park. Witnessing a fight in the open might give us a feeling of eavesdropping into other people's private matters. We might feel uncomfortable and we might not want to hear the content of the fight, although we cannot but hear what takes place. In this light, stopping by an open window to listen is regarded as bad manners. Let's say that the fighting couple are at home with an open window and the next door neighbour not only listens to the content, but posts the content on Facebook. Not nice, we would say, but has he violated a right, if the right has been waived? Still, we would want to say that recording it is inappropriate and that there is a violation of social norms of privacy; norms that state that we should not make a point of listening to personal conversations wherever they take place.

What seems to matter here is not just where the action takes place but also the nature of the conversation and the relationship between the couple. The couple might keep the windows closed but still we might hear, perhaps not as clearly but we could still hear. Have they still waived their right because they have not kept their voices down enough?

Take another example. Simply having an opportunity to listen to a conversation or reading something does not necessarily justify us doing so. Let's say that my friend forgets her personal diary at my home. If she has a right to privacy in regards to her diary we may argue that by carelessly leaving it at my kitchen table she has waived her right. Nevertheless, the diary is private and reading it requires certain action on my behalf. Is the difference between the fighting couple and the diary that I have to make a point of opening the diary to read it, but I cannot help but hear the fighting couple from the street? What is important here is not only distinguishing between violation of rights and bad manners, but the nuances in different contexts.

Respecting privacy is about recognizing the need for space. Similarly, a neighbour hearing something from the next door apartment would hear without hearing hoping that others would do the same. Let's say that we live in an apartment building with several flats. One person living in one of the flats makes a point of listening to all the fights, arguments and scolding that are going on in the building. As soon as she hears something from another apartment, she makes a point of finding a place in the building where she can best hear what is going on. She is not using any devices but manages to keep track of most of the fights going on in the building, even keeps notes of the dates of the fights from each apartment, who are involved and the content of the arguments. At annual garden parties she refers to this information in her conversations with others. Such a person would definitely not be complying

with our privacy norms of not listening. She is like Diogenes, going against the norms, or not sensitive to the social structure and conventions. However she is not violating any negative rights, it seems.

This also connects with the discussion of donating genetic samples to a biobank. If privacy is a right of non-interference, it seems that we have waived the right once we donate our genetic data to a biobank. However, as I discussed in the last chapter, privacy concerns arise after the sample has been shared and donated: how it will be used and what possibilities for usage will there be in the future. To meet these challenges we need a structure or social norms to protect privacy in this context. Similarly, there is a good reason for arguing for privacy in public; that in some cases at least, information gathered in the public space should not be circulated or used in a different context. Nevertheless, within the framework of rights of non-interference, we seem to have waived our rights to privacy in regards to behaviour in public.

Claiming we have rights in the above cases, or that we have waived our right to privacy, is not really picking up what is interesting about these examples in relation to privacy. In all these cases our examination of privacy depends on the social structure or social context. It is not the case that we either have a right to privacy in relation to a conversation in the park, or that we have waived the right; there are many nuances we need to take into consideration. These nuances must be explained against a background of social structure and reasonable expectations. Thomson's example shows that how we define the case depends on the social structure, and also that there is a fine line between bad manners and privacy violations.

## *5.2 Positive rights and obligations*

Although negative rights of non-interference seem to connect naturally with the traditional understanding of privacy as perceived in the separation and control models, the framework of rights fails to address important social aspects of privacy. According to many liberal theorists, negative rights is the only framework that has the moral clarity needed to give privacy interests a proper grounding or moral force. Positive rights have been dismissed as lacking universality and normative force. However, as I have argued throughout the thesis, many privacy interests arise when we share information with other individuals or institutions, such as in our relationship with our family doctor or when we donate our sample to a biobank.

As explained earlier there is more to rights than what is included in negative rights and advocates of negative rights have been criticized for giving a simplified version of rights, downplaying the importance of obligations of others and the social structure. Henry Shue argues against making a sharp distinction between negative and positive rights. He argues that we need to focus on obligations rather than rights, and once we do that we see the importance of institutions for all rights, including negative rights. Another writer, Onora O’Neill, argues for starting with obligations and institution building. Her distinction between imperfect and perfect obligations will be helpful.

### *5.2.1 Criticism of the distinction between negative and positive rights*

Henry Shue denies both the distinction between negative and positive rights, and the view that political rights are more basic than economic rights, or what he calls subsistence rights.<sup>253</sup> Shue argues that the enjoyment of what he calls basic rights “is essential to the enjoyment of every other right”.<sup>254</sup> This means that we cannot enjoy any other rights unless our basic rights

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<sup>253</sup> Shue (1980).

<sup>254</sup> Shue (1980) p. 19.



have been fulfilled. According to him there are three basic rights: a right to physical security, a right to subsistence and some kinds of liberty rights. If these rights are not fulfilled or if they are sacrificed, we thereby sacrifice any other right.

Shue rejects the distinction between negative and positive rights because it overlooks the fact that all rights require what he calls ‘social guarantees’; namely, some positive action or social structure. He discusses, for instance, the right to security, normally viewed as a negative right which simply requires that others leave us alone, that they do not attempt to assault us, rape or murder. Shue, on the other hand, explains how this is far from being the whole story. Explaining the right to physical security as a negative right only shows how we avoid violating the right but not how the right should or could be protected.<sup>255</sup> If we really want to protect physical security, we need to establish social institutions such as a police force and criminal courts, all of which require positive actions. We live in an organized society which means that we do not only happen to have the right to physical security, because people refrain from assaulting us, but that there are social structures which guarantee and protect this particular right. Similarly, the right to subsistence not only requires positive action on others’ behalf; on the contrary, sometimes it simply means that we do not interfere with people’s lives in such a way that it makes it impossible for them to provide for themselves – or as he states: “All that is sometimes necessary is to protect the person whose subsistence is threatened from the individuals and institutions that will otherwise intentionally or unintentionally harm them.”<sup>256</sup> If we look at rights in this way, we see that it is not the case that positive rights are costly but negative rights are not, nor that positive rights require action where negative do not. On the contrary – all rights require that certain things or services are provided.

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<sup>255</sup> Shue (1980) p. 37.

<sup>256</sup> Shue (1980) p. 40.

Consequently, Shue states that the positive/negative distinction is not between rights but between positive and negative duties that correspond to rights. Moreover he argues that the basic rights (and possibly all rights) involve fulfilment of multiple kinds of duties.<sup>257</sup> Shue introduces three correlative duties to every basic right: 1) duties to avoid depriving 2) duties to protect from depriving 3) duties to aid the deprived.<sup>258</sup> This sets duties into focus and he argues that fulfilment of basic rights needs some kind of social structure or institutions. In the absence of such institutions there is little chance of enjoying rights, negative or otherwise. “To enjoy a right is to exercise it within institutions that effectively protect one against deprivation of it, especially deprivation by those with the most power in the situation”.<sup>259</sup>

The merit of Shue’s argument is that he directs the focus towards duties and social institutions needed for us to be able to talk meaningfully of having rights. Freedom does not only require being free from certain kinds of intrusion, but also to have meaningful choices supported by social institutions. In modern societies with complex structures and institutions there are both more possibilities to enjoy privacy but also more varied threats of loss of privacy. We need therefore to understand privacy in relation to these institutions: what obligations arise within them and how privacy is protected within such institutions. Privacy is not primarily about staying away from others in a sphere of non-interference, but about defining obligations in different relations. Having a right to privacy in relation to our doctor or when donating a sample to biobanks means that we need to specify these obligations as part of our social institutions, and therefore privacy rights cannot be thought of merely as negative rights.

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<sup>257</sup> Shue (1980) p. 52.

<sup>258</sup> Shue (1980) p. 52.

<sup>259</sup> Shue (1980) p. 81.

### 5.2.2 *O'Neill: obligations and trustworthy institutions*

Onora O'Neill argues in a similar vein for obligations rather than rights.<sup>260</sup> Without making the strong claim that obligations are more fundamental than rights, O'Neill states that obligations are the anchor for rights: to take rights seriously is to take obligations seriously.<sup>261</sup> She acknowledges that the perspective of obligations may not be as politically enticing as that of rights, but they are "more realistic, clear and honest about burdens, their justification and their allocation".<sup>262</sup> O'Neill relates obligations to principles of action and trustworthy institutions. In this discussion I will focus on four issues in O'Neill's theory: 1) obligations are relational and put into focus the actions needed to meet rights; 2) obligations give a better understanding of the distinction between negative and positive rights; 3) obligations introduce a broader framework with both perfect and imperfect obligations, than when we start with rights; and 4) obligations must be based on universal principles that everyone can follow. I will now discuss these issues briefly and take them up later in relation to privacy.

First, the advantage of starting with obligations, instead of starting with rights and the claims or entitlements to something, is that obligations direct our attention to the ways in which rights can be met and protected.<sup>263</sup> This brings forth an important feature of obligations: they are always talked about in the language of action; they state immediately what a person should do or refrain from doing. This means that obligations are relational; that is, they direct attention to the relationship between the rights holder and the obligation bearer. Furthermore the advantage of the obligation approach, according to O'Neill, is that it is easier to sort substantial claims for rights from illusory ones. O'Neill compares the difference

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<sup>260</sup> O'Neill (2002), O'Neill (1996).

<sup>261</sup> O'Neill (2005) p. 430.

<sup>262</sup> O'Neill (1996) p. 135.

<sup>263</sup> O'Neill (1996) p. 127.

between the right to health and the right to health care to illustrate this point. When we try to define the obligations corresponding to the right to health we realize its dubious standing and it seems like the right is dangling in the air.<sup>264</sup>

Second, O'Neill criticizes the distinction between positive and negative rights but, unlike Shue, she argues that positive rights of goods and services are in important ways different from negative rights. According to O'Neill, the duties corresponding to rights to goods and services must be allocated to someone, since we cannot all have the duty to fulfil such rights – like providing education or health care. Evidently rights to goods and services cannot be universal, not only because only a few of us would be able to meet the obligations, but also because if we all tried to meet them it would lead to chaos.<sup>265</sup> Therefore we need to specify who has the obligations in such cases. The question is, however, against whom? Unless rights to goods and services have been allocated to individuals or institutions we do not know where to press our claim – and it is unclear if there is anyone who has violated a right.<sup>266</sup> Therefore rights to goods and services take on a different form, because the corresponding obligations must be distributed and allocated unlike liberty rights. The rights to goods and services must be institutionalized and allocated to someone in particular; otherwise, there is no right.<sup>267</sup> “Without institutions the rights to goods and services are incomplete. Institutions are necessary to define and allocate obligations”.<sup>268</sup>

Third, the conceptual link between rights and obligations goes one way: all rights must have a corresponding obligation. However, the same is not true of obligations; as O'Neill describes, there are obligations that do not have corresponding rights but refer rather to

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<sup>264</sup> O'Neill (2002) p. 79.

<sup>265</sup> O'Neill (2000) p. 102.

<sup>266</sup> O'Neill (2000) p. 125.

<sup>267</sup> O'Neill (1996) p. 135.

<sup>268</sup> O'Neill (1996), TJV, (p. 132).

virtuous actions, called imperfect obligations. Focusing only on obligations or duties corresponding to rights, other obligations fall outside this scope and generate an impoverished view of morality.<sup>269</sup> O'Neill uses Kant's distinction between perfect and imperfect obligations to explain the differences between these different obligations. Perfect obligations are the ones corresponding to rights and imperfect obligations have no such corresponding rights but have corresponding virtues. This difference shows that perfect obligations provide a minimum standard of something we owe but imperfect obligations provide for more. They refer to the character of the individual. Unlike rights we cannot make a claim to show virtuous behaviour. These two categories of obligations are divided further into universal and special obligations. The former are obligations that everyone can hold; the latter grow out of special roles and institutions.

Consequently, there are four types of obligations: perfect and imperfect, and each can be either universal or special. 1) *Universal perfect obligations*. These obligations are held by all others and have counterpart universal rights. The paradigm of universal rights corresponding to perfect obligations is liberty rights of non-interference; 2) *Special perfect obligations* corresponding to special rights. Here we have rights to goods and services which need to be institutionalized to have content. The right to health care is of this type, where we must be able to allocate the obligation to particular institutions or individuals. Similarly, a child has a right to be fed and cared for by his or her parents, or specific others if the parents fail to meet their obligations; 3) *Universal imperfect obligations* are different because they do not have corresponding rights but instead have corresponding virtues. Such obligations are held by all but owed by none. Many of the important traditional virtues are in this category such as

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<sup>269</sup> Raz (1984) and O'Neill (1996).

honesty, fairness and beneficence.<sup>270</sup> Helpfulness is an important virtue in our lives; we may not have a right to be helped by others if we fall on the street, but still there is a duty of those around not simply to ignore us and pass by. 4) *Special imperfect obligations* are grounded in special relationships and therefore held by some but owed to none. Parents not only have the perfect obligation to provide for the needs of their children but also to be considered and loving.

Later in this chapter I will discuss privacy in relation to these four categories of obligations. Of these categories 2), 3) and 4) are especially important. 2) is important because it focuses on institutions and therefore applies to some of the cases I have discussed in this thesis, such as the doctor-patient relationship and biobanks; 3) is important for all kinds of informal relations where privacy is appropriate and I have discussed several throughout the thesis, and 4) has to do with special relationships such as friendship which are importantly based on a sense of privacy.

O'Neill's overall aim with her account is to bridge the gap between particularists, who focus primarily on virtues of particular situations or relationships, and universalists, who argue for universal rights and justice independent of various situations and contexts. Starting with obligations keeps all obligations in the picture and provides an opportunity for talking both about universal rights and particular virtues. Whereas starting with rights gives an impoverished understanding of ethics since it fails to include virtues as a part of our ethical reality.<sup>271</sup> As will be discussed later some of the privacy concerns we have in everyday life correspond to virtues in this way.

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<sup>270</sup> O'Neill (1996) p. 137.

<sup>271</sup> O'Neill (1996) p. 124.

Fourth, O'Neill points out that at the same time that trust seems to be diminishing, there is a growing emphasis on individual autonomy and rights. She criticizes what she labels as individual autonomy, or the capacity of an individual to make choices about his or her life. This account of autonomy, i.e. individual autonomy, has become most fashionable in contemporary bioethics. One of the most important features of individual autonomy is a state of *independence*, that is, a state of being able to engage in independent decision and action. According to O'Neill trust and individual autonomy are pulling in different directions and hence individual autonomy is one of the reasons for growing distrust.<sup>272</sup>

Kant is often seen as the source of individual autonomy as represented in contemporary ethics. In her highly interesting interpretation of Kant, Onora O'Neill rejects this interpretation as misdirected. Surely autonomy plays a central role in Kantian ethics but, O'Neill argues, his account of autonomy "is manifested in a life in which duties are met in which there is respect for others and their rights, rather than in a life liberated from all bonds."<sup>273</sup> In short, O'Neill argues that it is not individual autonomy that he is interested in but autonomy of reason or ethics. This means that acting according to autonomy is to act according to principles that are fit to be universal laws.<sup>274</sup> Acceptable principles must pass the test of being principles that everyone could act on or adopt as their own; they must be intelligible to others and able to guide action. If taken seriously principled autonomy is committed to a set of principles which reject deception, coercion and manipulation. Someone who wills the principle of coercion as a universal law, for example, "must also will that everybody use some effective means of coercion".<sup>275</sup> But such a claim is incoherent; it is not possible that everyone is coercing

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<sup>272</sup> O'Neill (2002) p. 25.

<sup>273</sup> O'Neill (2002) p. 83.

<sup>274</sup> O'Neill (2002) p. 84.

<sup>275</sup> O'Neill (2002) p. 87.

because the result of coercion is that someone else cannot act in such a way. The principle has internal contradiction and therefore we must accept the principle of non-coercion. Furthermore, O'Neill argues that obligations and principles are important in outlining a blueprint for institution building".<sup>276</sup> Institutions are supposed to specify how rights can be met and protected and the focus is therefore on obligations. The symmetry of rights and obligations is evident only in the case of universal liberty rights considered in abstract, but not in other cases where obligations must be allocated. To build trustworthy institutions they must be grounded in the general principles such as not to deceive, manipulate or coerce.

The reason I have dwelt on O'Neill's account of obligations, principles and trustworthy institutions is that she presents an alternative framework to the one grounded primarily in rights of non-interference. In this thesis I have argued for privacy as a relational concept depending on others rather than as a claim against others. Privacy claims are within a society not apart from it, and depend on how other people or institutions behave. If privacy depends on others, then we need to specify what the others are supposed to do and obligations are put in focus. Having privacy means that we must specify the relations we have and what kinds of obligations privacy involves. Starting with obligations focuses on what is needed for privacy to be protected. Furthermore, the distinction between perfect and imperfect obligations gives broader perspective including personal, professional and social relationships. We enjoy privacy not only in private settings of personal relations, but also in professional relations such as doctor-patient or when we share information in biobanks. This means we need to find ways to build institutions that are worthy of trust. Privacy therefore not only depends on trust in private settings but in social settings as well. These issues will be discussed below.

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<sup>276</sup> O'Neill (1996) p. 135.



### *5.3 Trusting within the private and the public*

Some privacy advocates have argued that privacy connects to trust. In chapter 3 I discussed Kupfer, who argues that when we are allowed to be alone or attend to our own things, that is a sign of trust from others.<sup>277</sup> Benn, in his analysis of privacy, argues that we need a closed-off space where we are not influenced by social pressure: a private space which makes it possible for us to “drop the mask,” a space which allows us to behave differently than we might do either in public roles or in front of strangers.<sup>278</sup> The background to this thought is that we behave differently when we are alone or in a trusted environment than we do in the company of strangers. We are more relaxed in a private space and are able to show a different side of our character. Benn argues further that having a private space is not only an important condition for being able to control our public appearance, but it is also important for our mental health. “To remain sane,” he states, “we need a closed environment, open only to those we trust, with whom we have an unspoken understanding that whatever is revealed goes no farther”.<sup>279</sup> Here Benn presupposes that there is a space or sphere of non-interference – a haven or sanctuary closed off from the outside world. When we share things with others we are vulnerable and therefore we need to be in a trusted environment. It must be stressed that here Benn is only talking about trust in relation to privacy, but not stating that we have no trust in the public. Nevertheless, his view indicates a suspicion of the public, where the public is seen as a threat. This suggests that we cannot trust people in public in relation to our privacy.

If Benn is right and privacy needs trust in an important sense, and the only trusted environment available for privacy is in private, then we cannot have privacy in public. However, as I have argued in this thesis, privacy in public can be an important value.

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<sup>277</sup> Kupfer (1987).

<sup>278</sup> Benn (1971) p. 24.

<sup>279</sup> Benn (1971) p. 25.

Furthermore, our privacy needs to be protected not only in private relationships but also in public institutions and public interactions. Therefore, the question is if and how we can construct trusting relationships in public or build social trust – more accurately, how can we build trustworthy institutions?

### *5.3.1 Social trust*

Trust has been described as the glue of social life.<sup>280</sup> Trudy Govier in her book *Social Trust and Human Communities* gives a general account of trust that consists of the following four features: 1) expectations of benign, not harmful, behaviour based on beliefs about the trusted person's motivation and competence; 2) an attribution or assumption of general integrity on the part of the other, a sense that the trusted person is a good person; 3) a willingness to rely or depend on the trusted person, an acceptance of risk and vulnerability; and 4) a general disposition to interpret the trusted person's actions favourably.

Therefore trusting a person means that we believe he or she is going to live up to certain expectations. Trust is an attitude or a belief about the future. It is an optimistic belief about what will happen because the future is uncertain. Govier argues that we need to be able to trust and she discusses examples of professionals, public institutions, and our trust of complete strangers, which are different from personal relations where our trust is based on experience. In our everyday interaction we trust that strangers are not going to do us harm. Also we trust professionals such as teachers when we send our kids to school, journalists when we read the papers and doctors at the hospital. As Govier says our society is depending on them to do their jobs competently and with integrity. Otherwise we are all vulnerable.<sup>281</sup> As Govier points out, trust is not absolute but rather we trust someone within a certain context. Trust is also open-

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<sup>280</sup> Govier (1997).

<sup>281</sup> Govier (1997) p. 106.

ended: we expect people to respond responsibly to our expectations even when they are not spelled out in detail. We trust a person to do certain things. We trust our babysitter to take care of our child while we are away; we trust our doctor to take our health issues seriously. Trusting someone does not only mean that we rely on another's goodwill but also that the person is sufficiently competent to live up to our expectations.<sup>282</sup> As such, the person has to be worthy of our trust. However it is worth noticing the broader social context given to trust or trustworthiness of individuals. The health care system provides the context in which we trust doctors, with its educational institutions and licensing of the people who practice. Therefore we are not only placing trust in one individual but in social institutions. Even with babysitting the community might give us such a social context in which we place our trust, for instance by providing babysitting courses for teenagers.

There is little consensus on how to define the concept of trust, and it has been described in various ways as a feeling, an emotion, a disposition, an activity, a knowledge, and a reliance.<sup>283</sup> Solomon and Flores distinguish between four types of trust<sup>284</sup>. Simple trust is taken for granted without any suspicion and reflection. It is innocent, remains innocent, and cannot be reflected upon. Basic trust usually begins without thought or reflection, is based on simple trust, and provides a general orientation or attitude to the world. Blind trust is essentially self-deceptive and involves denial in the face of obvious evidence. One sees but refuses to see. Authentic trust is open to evidence. It is a product of experience and commitment and carries with it the possibility of distrust.<sup>285</sup> Solomon and Flores argue that authentic trust is dynamic and open to new possibilities, as such trust is not given once and for all but is a choice that is

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<sup>282</sup> Baier (1986) p. 234-235.

<sup>283</sup> Sutrop (2007).

<sup>284</sup> Solomon and Flores (2001).

<sup>285</sup> Solomon and Flores (2001) p. 65-66.

made conscious of the possibilities of distrust. Given that trust can be blind, it is not always virtuous to trust; both trust and distrust can be rational and appropriate. Hence the literature on trust has focused on questions such as: Who is worthy of our trust? How can we build trustworthy institutions?<sup>286</sup>

### *5.3.2 Privacy and social trust*

The relation between trust and privacy is somewhat complex. It is safe to say that privacy concerns go hand in hand with a lack of trust in many fields of our society. It seems like privacy concerns are partly voiced because people are experiencing a lack of trust in social settings. As was discussed in chapter 4, in modern societies there are numerous ways of storing personal information and using personal data – for marketing, research interests and to discipline people in public spaces. Therefore, there is a growing concern among the public whether social agents and institutions are worthy of trust. We wonder if it is safe to use our credit card in the supermarket, whether to give our credit card number over the phone or the internet, if our e-mails are read by third parties or our employer, and if we might become victims of identity theft. In a world of modern technology, the answer to our privacy worries is not necessarily diminishing intrusion and having more space or less physical access to others. We may well feel more secure in bigger flats or fenced-off properties, but we still have the internet hooked up in our houses, cell phones open and the credit card at hand. It looks like we need to rely on other measures for protecting our personal data.

We have seen the relations between trust and privacy within the public and trust is needed both in public as well as private settings. It is certainly true that we are seen by many people, mostly strangers in open public spaces. When we do our shopping in the market or the

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<sup>286</sup> Hardin (1996).

mall we are not trying to hide our activities. In spite of this, we do not expect that our activities will be recorded by governmental authorities or made public in the media. Although public streets are open to everyone, they are public in a different sense than the media. Not only are more people viewing the media than are in a public street, they are focusing on what is there which makes the viewing more intense, and what has been documented in the media can be read or viewed over and over again.

Therefore it seems that we trust strangers every day with our personal information just like we trust people not to rob us, drivers not to run us down on crosswalks or stores not to rip us off.<sup>287</sup> We take trust for granted and do not think about it until we experience distrust. The strangers we interact with in our daily life are often just people like us; we share information or space with others and both parties are equally vulnerable. However some strangers we meet represent big business and corporations. Big stores, banks and computer companies receive our personal information every day. These companies set the terms for doing business and individuals may find themselves utterly powerless in relation to them. This does not leave the individual with much control or many choices. If we want to use the technology and their service, we can either go along with their terms, and hope that they are trustworthy, or we can push for governmental institutions or regulations to help ensure that they are trustworthy.

Despite growing concerns for privacy among the public, it has been pointed out that people often seem willing to compromise their privacy. Many technical devices in modern society may facilitate surveillance, such as credit cards, cell phones and caller ID. Nevertheless people most often choose credit cards over cash, e-mail rather than the post. Sometimes there is no choice as in securing hotel rooms, renting a car or buying tickets at

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<sup>287</sup> Govier (1997).

Ticketmaster. So even though people say they want privacy, what they do expresses quite the opposite.<sup>288</sup>

Surely we often compromise our privacy in modern society. Nevertheless, when we give someone our personal information we do it in a certain context or social setting, and we have certain expectations of how the information will be used or handled. When we share information with our friends and relatives we do so because we expect them to respect it. When we rely on professionals we trust them to keep our personal information in confidence. And even outside intimate or formal professional settings there is always a background of expectations and trust. For instance, when we hand over our credit card number when paying for our purchase we expect that it will be used only for that purpose and no other. When we give the pizza place our phone number we only do that so it can verify our order, but not to sell it / give it to someone who is collecting phone numbers of families or single women in the neighbourhood. From this we see that we always give our personal information in a context of some background expectations, and where we trust the receiver of the information to treat it accordingly. Therefore we need to be able to trust that people and institutions live up to their obligations, expectations or social norms.

### *5.3.3 Privacy and distrust*

We often take trust for granted and do not see its value until we experience the opposite condition, distrust. “It [distrust] exists when there is a lack of confidence in the other, a concern that he or she may act as to harm us, that he or she does not care about our welfare, intends to act harmfully, will not abide by basic moral norms, or is hostile towards us. When

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<sup>288</sup> Nissenbaum (2010) p. 104.

we distrust, we are fearful and suspicious about what the other might do.”<sup>289</sup> Sharing privacy needs trust; conversely, lack of privacy or surveillance is a sign of distrust.

Govier discusses the totalitarian society, a paradigm state of distrust with extensive surveillance. In the totalitarian society there is no sphere that is not subject to governmental intrusion; there is no civil society, no way of sharing information in trusted relations. This indicates that there is an important connection between trust and privacy. If we do not trust someone we want to know what he is up to.<sup>290</sup> In the totalitarian society there is a constant threat of the state and there is constant surveillance. In such a society there is no trust between individuals and public institutions, and therefore no conditions for sharing information in a trusted environment. In such a society, privacy becomes secrecy.

Surveillance is both a sign of distrust and fosters distrust.<sup>291</sup> Employers have various ways of monitoring their employees. One way is to make drug testing a standard routine. The justification often given for such testing is to prevent harm to others.<sup>292</sup> However, such testing conveys the feeling that the workers are not trusted, and studies have shown that by using such surveillance employers risk receiving distrust or lack of loyalty in return from the employees. Hence drug testing may lead to suspicion on behalf of both parties, since distrust elicits distrust. Whether surveillance is justifiable depends on other values. It is easier to accept a lack of privacy and surveillance if we believe it is facilitating our own security. This is also true in other contexts; think, for example, of airports, where extensive surveillance is largely accepted by travellers because they believe it makes travelling more secure.

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<sup>289</sup> Govier (1997) p. 34.

<sup>290</sup> Another form of society which invades privacy is the gossip society according to Margalit (1996) p. 204.

<sup>291</sup> Tunick (2001) p. 527-528.

<sup>292</sup> Desjardins and Duska (2003).

Although surveillance is seen as a sign of distrust in public, some have argued that too much privacy undermines quality of public life or community for at least two reasons.<sup>293</sup> If the private sphere is the sphere of human flourishing, the public sphere becomes less important. This may affect social interaction and relations between people. Privacy is also seen as undermining community because it can be a shelter for illegal or anti-social behaviour.<sup>294</sup> When it is easier for individuals to shelter, or be away from others, it is harder for the authorities to investigate crimes and protect the public from criminals. However these views depend on a certain understanding of privacy and the private sphere.

Those who criticize privacy for undermining community generally understand privacy as a license.<sup>295</sup> This rests on the notion of self-centered individuals who take only their own interests into account. Privacy claims are claims about controlling access by others, about being able to withdraw from the observation of others, and about having one's own space. Privacy is a matter of our choosing when and to whom we reveal our personal information, and as such it has been seen as an adversarial right – the right to be left alone. It is voiced as a claim against others. As we saw earlier O'Neill criticized independent autonomy for focusing too much on independent individuals, and she argues further that it has implications for trust. Accordingly, independent autonomy is pulling away from trust.

Similarly, privacy understood as isolation or seclusion from others undermines social relations. In isolation people do not need to take others into account, which can lead to anti-social behaviour. Individualistic accounts of privacy undermine trust in an important way. In this thesis I have emphasized how privacy depends on social norms and practices. Privacy takes place within the community and depends on others; it is not a state of isolation. Privacy

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<sup>293</sup> Solove (2008) p. 81.

<sup>294</sup> Etzioni (1999).

<sup>295</sup> Tunick (2001) p. 523.



refers to relations between people, when we actively give space, leave people to be, respect information. Therefore we need to identify the obligations that refer to privacy interests. If we understand privacy as an obligation, we are able to see the public life as a source of worthwhile life.<sup>296</sup> We need to build trustworthy institutions to truly be able to exercise privacy.

#### *5.4 Social privacy and trustworthy institutions*

I have argued that privacy is about how we share information or space in different relationships – in relations with strangers, in intimate relations of family or friends, and in professional or public relationships. Privacy is a relational concept, similar to obligations, directing the attention to how we interact with others and what actions are required to protect privacy. Furthermore privacy depends on expectations we have of others: that people comply with social norms and ethical principles.

In this section I want to use O'Neill's types of obligations to identify the obligations of different privacy relations and outline how O'Neill's account of principles of justice and virtues can be applied to them. As we saw earlier the principles underlying imperfect and perfect obligations are different. Perfect obligations are a matter of justice and have corresponding rights but imperfect obligations are a matter of virtues. Identifying obligations is also needed to create conditions of trust or trustworthiness necessary for such relations to flourish.

##### *5.4.1 Privacy and imperfect/perfect obligations*

*Universal imperfect obligations* refer to general virtues very much valued in our personal and social interactions, virtues such as toleration, care, and concern. Some of the examples I have

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<sup>296</sup> Tunick (2001) p. 527.

discussed in this thesis refer to privacy in this sense, where we give space in social settings – and hence space for privacy. There are social norms and practices that protect privacy. We have social norms that define how it is appropriate to behave on the bus or in the park; for instance, we are not to read over someone’s shoulder or to sit too close to someone on the park bench, if there are seats farther away. Neither are we supposed to stare at people or closely scrutinize them in public. We do not have a claim against people that they behave in such a way and therefore these norms are held by all but owed by none. We can take, for instance, the case of the Inuit that has been discussed several times throughout this thesis. They give each other space by looking away or see without seeing. Acting in accordance with these rules everyone is sustaining privacy within the community and preserving social fabric, making it possible to have privacy within a crowded environment. This is an example of actively giving space, paying attention to the need for privacy without paying attention to the actions taking place. People trust others in the community to give space for certain actions without improper interference.

O’Neill identifies four categories of virtues of which social virtues are most important in this context, especially those that sustain social trust.<sup>297</sup> Social virtues form our social relationships and are virtues such as toleration, trust and openness. They are based on the principles of rejecting indifference and neglect; these principles can be universalized even if we can only show care for some people but not all. This means that they leave open to whom, or when, or in what ways virtue is to be expressed.<sup>298</sup> Privacy in informal everyday interactions is importantly a part of the social fabric and is supported by various social virtues rather than a particular one: virtues that take others into account such as tolerance and trust.

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<sup>297</sup> O’Neill (1996) p. 187-189 and p. 202.

<sup>298</sup> O’Neill (1996) p. 195.

People who are considerate are more likely to respect privacy of others, and it makes the public space more comfortable for all if we act according to privacy norms. These privacy norms are embedded in the social structure, something we learn to accept and respect, and something that can differ from one society to another. Therefore privacy has to do with how the shared space is structured and defines basic virtues of interaction. We trust others to act according to these virtues and to allow us to go about in our everyday life without interference--just like the Inuit trust that others look away and give space. Therefore privacy obligations require that we support social fabric by complying to the social norms that protect privacy.

*Specific imperfect obligations* refer, as universal imperfect obligations, also to character and virtues, but they arise because of certain roles we have with others. Roles like being a parent, a partner, a friend or a neighbour are primarily defined by social structure and social practices. Some of these roles such as being a spouse or a friend are importantly based on privacy; for other roles, privacy may be less important, yet still privacy has its place. The privacy interests we have in personal relationships take on different forms. We need to be able to confide in our friends and family, share our thoughts and interests. For instance, a good friend does not read our personal diary although we leave it accidentally at her house; a spouse does not read the other spouse's e-mail. We also share space in intimate ways with friends and family and need to both give space and be given space by others. We both share intimate space and give space in such relationships; we share information and also keep away from prying. Therefore the virtues of private relationships are confidentiality and reticence.

Privacy in personal relationships is about demarcating boundaries between different individuals, how we present ourselves to others. Being a friend means that we create an

atmosphere of trust where information can be shared or not shared. Although confidentiality is implicit in friendship, our personal relationships with others are defined by the individuals involved. The nature and depth of our relations to our friends varies and so do our expectations of others. Nevertheless some degree of confidentiality, support and care is needed for any friendship. Again, in such cases we do not have a privacy claim on others but rather respect for privacy is what distinguishes good relations from bad ones.

*Special perfect obligations* correspond to what we often call welfare rights or rights to goods and services. These obligations require social structures and practices that connect specific agents to specific recipients of action.<sup>299</sup> These obligations need to be allocated to particular institutions or individuals. Rights to informational privacy, such as genetic privacy, very often take this form. Sharing information in a doctor-patient relationship or donating a sample to a biobank are cases that fall into the category of specific perfect obligations. In both these cases obligations must be defined within a particular context which requires structure and allocation of obligations. We share information with our doctor in the context of doctors' confidentiality. This context is defined by the ethos of the practice, is part of doctors' education, grounds licensing of the profession, and is specified in professional guidelines. Thus when we confide in our doctor, we are not confiding in an individual but in an individual who is a part of this institution of doctors. Doctors' confidentiality holds in all circumstances and long after the relationship between the doctor and the patient ends. The principle of confidentiality is more explicitly spelled out in the case of doctors and must be applied in the same way to all doctor-patient relationships, unlike in personal relationships. The trust we have for doctors' confidentiality is grounded in the institution and breach of confidentiality

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<sup>299</sup> O'Neill (1996) p. 147.

does not only affect one individual as in personal relations but can affect our trust of the institution. We trust a doctor as a part of an institution to treat all our correspondence as confidential; any exception to that rule must also comply to the practices of doctors. Therefore these relations are much more rigid than personal relations of friends or intimate relations of partners.

Similarly, when we donate our DNA sample to a biobank for genetic research we do so against expectations that our sample will be used for medical research – research that has a public benefit, is performed by competent researchers, is executed in accordance with ethical standards, and monitored by relevant agencies. Unlike the institution of doctors where practices have been developing for centuries, practices of biobanks are recent and therefore expectations from participants may be unclear to a degree. As we have seen, information technology has introduced new ways of storing and using personal information. For many such usages we do not have proper norms or ethical standards in place. Therefore we are not sure if big corporations are collecting information from stores or financial agencies and in some cases such norms are late in development.

*Universal perfect obligations* refer to the right to privacy held by all others. According to O'Neill we have here traditional liberty rights. This category of obligations is least important for my understanding of privacy. However, we must remember that rights are important when things have gone wrong.<sup>300</sup> Jeremy Waldron argues that although rights may be out of place in many relationships, such as in marriage, they may still be necessary to fall back on if the relationships change or fail for some reason. In this context we may need an impersonal framework of rights apart from communal attachments. Another reason rights may

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<sup>300</sup> Waldron (1988).

be necessary in social contexts is to initiate new relationships. In the case when the social structure is immoral or wrong we need to be able to voice our rights and claim for change, then rights “provide dynamics for social progress.”<sup>301</sup> An example where we might need rights to fall back on is the construction of biobanks following discoveries of the DNA. As I mentioned earlier, before the discovery of the DNA structure there was no reason to have privacy concerns in relation to our bio samples. Once the knowledge and technology is there, the claim for privacy may be voiced as a right in the absence of regulations or guidelines.

This shows that the four types of obligations pick up the diverse privacy concerns that have been discussed in this thesis. Only some of the concerns can be protected as rights and perfect obligations; others refer to virtues and character, how considerate we are in everyday interactions. Nevertheless these virtues are important. We do not have a right against someone eavesdropping into our private conversation at the park, but our social lives and daily interactions become more comfortable and relaxed when people comply with these norms. We also see that one of the most important cases I have discussed in this thesis, the concerns arising from information technology, turn out to be universal special obligations.

I do not argue that the different cases of privacy rest on unified conception of privacy; nevertheless, they bear some resemblances. They have to do with how we present ourselves in relation to others, both physically or in physical space and how we share information with each other. As we have seen this takes on a different form, whether on a personal or a professional basis. When we share information or space we make ourselves vulnerable to other persons, who again in some cases become vulnerable to us, in the way that exposure or disclosure can be harmful. The harm associated with such privacy violations has to do with

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<sup>301</sup> Waldron (1988) p. 631.

how we are viewed by others, and therefore can cause reputational harm or social harm. O'Neill argues that vulnerability is important for trust and in the case of personal relations our vulnerability is often mutual. The same is not the case with institutions or the state. Therefore it is an important feature for building trustworthiness that there is risk or vulnerability on both sides.

#### *5.4.2 Principles, justice and virtues*

One reason we are especially vulnerable to privacy violations or breach of confidentiality, exposure or disclosure is the fact that complaining about such violation may risk wider disclosure of information. Someone who complains about a doctor's violation of confidentiality or publication of personal information in the media draws further attention to the personal information by complaining. This draws attention to the question of how we can cultivate the principles that protect privacy and prevent the harm associated with privacy violations.

We have seen how O'Neill distinguishes between perfect obligations of justice or rights and imperfect obligations of virtues. This allows for a broader ethical concern – what is of interest is not only justice and rights but also individual attitude and character. I have argued that different privacy concerns can be applied to the framework of obligations. This means that privacy corresponds to both virtues and rights, especially positive rights: to protect privacy we need social norms in place and trustworthy institutions. In this final section I will sketch an outline of O'Neill's account of principles of justice and virtues and apply them to privacy. My focus will be on specific perfect obligations of trustworthy institutions but still a few points need to be stated about virtues.

The principles that reject indifference and neglect require virtuous actions such as care and consideration of other people. I have argued that social virtues protect privacy by cultivating communal norms and social fabric. These virtues support privacy interests both in informal interactions and in personal relations. Here we have norms that demarcate the public and the private in everyday actions but they cannot be spelled out in detail. Virtues are characteristics of individuals and as such virtuous principles are inclusive because they go through different spheres. Someone who is in the habit of respecting privacy of others in his or her personal life is likely to do so in professional life as well, not only because such an act is required by the professional institution but because it is in his or her character to do so. Specific obligations of institutions meet minimal standards rather than require for virtuous actions. Doctors are required to keep all information confidential but privacy is not only about information but also about how we give space in everyday practice, how we see without seeing and show respect in everyday interaction. Complying with such norms in everyday interaction should also influence the practice on an institutional level even if they cannot be institutionalized in the same way.

The principles of professions or institutions need to be spelled out more carefully than is possible in relation to virtues. We have seen that confidentiality is an important principle of professional institutions such as doctors. Other important principles include transparency or openness. According to this principle we should be informed of the basic practices of the profession, what is implicit in confidentiality, how information is kept and how it is used. The principle of transparency or openness has taken on many forms in relation to information technology.



I have already mentioned that O'Neill identifies principles, such as the one which rejects deception, coercion and manipulation. These principles are fit to guide the actions of all. These principles also facilitate trust and trustworthy institutions. But can we identify principles for privacy based on O'Neill's analysis of justice? When discussing the case of Truman and the panopticon we saw how important it is for privacy to reject deception and manipulation. One of the objections to many technology devices is that sometimes people are unaware of their existence or are unaware of what using them constitutes. Surveillance with cameras can be totally unnoticed, and people using the internet may be totally unaware of the surveillance taking part. Thus we are often deceived of the fact that we are being watched, our conversation recorded or our whereabouts tracked. We have also seen how a lack of privacy can be used to manipulate individuals, for instance in the panopticon, where total surveillance is used to discipline people and alter behaviour. The principles O'Neill identifies are general and should guide all our actions, but are not specific to privacy. From them we can deduce the principle of transparency or openness about practices of institutions.

Nissenbaum argues that there are special principles in relation to informational privacy, and that one such principle is that of "appropriate flow" of information.<sup>302</sup> According to Nissenbaum, one of the main problems with information technology and privacy is that it is so easy to shift information from one context to another. For instance, genetic information gathered for medical research could be used for forensic purposes, without our consent or even knowledge. Nissenbaum argues that the main concerns people have in regards to informational privacy is shifting context: "it is a right to live in a world in which our expectations about the flow of personal information are, for the most part met; expectations that are shaped not only

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<sup>302</sup> Nissenbaum (2010) p. 187-188.

by force of habit and convention but a general confidence in the mutual support these flows accord to key organizing principles of social life, including moral and political ones.”<sup>303</sup> This means, for instance, that personal information collected for medical research should be handled with caution and should not be moved into totally different contexts such as insurance companies.

In a world of fast-developing information technology our expectations may change fast and it may be difficult to specify what norms should govern “appropriate flow” of information. Therefore more general principles such as O’Neill’s principles of non-deception and non-manipulation may be more satisfactory. Her principles would require that we have open and transparent procedures of information flow so that people would be aware of how their personal information is used, and if, or to what extent, the information would flow between different contexts. If individuals have an opportunity to opt out of such databases that might be the vulnerability needed for the directors to comply with ethical standards. Furthermore, we need monitoring bodies that will follow these procedures, monitoring bodies that are themselves trustworthy.<sup>304</sup>

As we saw when discussing informed consent in chapter 4 in relation to biobanks, the development of open consent and dynamic consent has been moving in this direction. Open consent is based on the principle of veracity, and proponents of open consent argue that it should be said explicitly when recruiting that privacy will be protected because most likely genetic sequencing makes people identifiable. According to this understanding of privacy, it ends with disclosure. People have really given up their privacy: people have lost control of this information or it is no longer hidden away from others. This is almost like blind trust. I have

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<sup>303</sup> Nissenbaum (2010) p. 231.

<sup>304</sup> O’Neill (2002b).

rejected this understanding of privacy in this thesis. Instead, we should see privacy as relational and sharing personal information in a biobank does not release researchers from responsibility and from ethical standards.

Unlike open consent, dynamic consent is constructed in such a way that it gives the donors the possibility of keeping track of their samples and their use over time. This is more in line with my understanding of privacy, where privacy standards continue after a sample has been donated, and individuals have opportunities to follow the use of the sample and possibly object or withdraw their participation. One may ask if such a device is a sign of distrust on behalf of the donor, if he or she does not trust the biobank to comply with acceptable ethical principles. However, this procedure makes the institution more vulnerable; it needs to have information on use available to the participants, and since the participants can opt out there are big interests at stake.

People might object to this understanding of privacy as being too dependent on social structure. Although we want to preserve the social fabric, in some cases the social fabric rests on unjust principles. In such cases it is significant to have the possibility of change or reform. Therefore, rights are still important for privacy protection. Rights are important when things have gone wrong but we need to cultivate principles to protect privacy and build institutions where privacy is respected and protected.

Therefore I argue that the social account of privacy is realistic and captures the social complexity of the concept. It states what is required to enjoy privacy and it requires mutual respect. If there is a lack of social norms or rules that people think they ought to comply with, then privacy is less valued in the society.

### *5.5 Conclusions*

Many argue that privacy is next to impossible in modern societies, because we do not have control of our personal information and because of all the technology we use. If we understand privacy either according to the separation model or the control model, then this may be the case. Moreover, we have seen that there are not many ways of amending the problem because within information technology it is almost impossible to secure restricted access or control. Then we have lost the battle before it begins.

Do we have more privacy if we understand privacy as social relations? My motivation has not been to give an account of privacy that makes it easier for us to argue that we have privacy, but to give a more realistic account. I deeply think that the ways in which privacy has been understood have been misdirected. I do not think that privacy as control or separation captures the core meaning of privacy even though they have some intuitive force. These models, as have been argued in this thesis, miss important features. The most recent arguments show that there is a deep frustration within the privacy literature regarding the understanding of privacy, and there have been many attempts to think about the concept in new ways. This thesis is an attempt in this vein. According to the social model of privacy we can and should define our relations with regards to privacy. Privacy is therefore still possible, but it is a big task to preserve it.

However, growing signs of distrust, for instance in workplaces or other institutions, break down the possibility of privacy relations. We are then not sharing information but forced to give information; information is exploited and we move towards a society of distrust. Often we complain of privacy invasions against the backdrop of changes in social norms.

Privacy is a social concept. It is about social relations and needs trust to flourish. I want to stress that all relations we have with others give rise to privacy issues. Whether we are in a

professional relationship, interacting on the Internet, standing at the bus stop or living with another person, all these relationships give rise to some privacy considerations – big or small, simple or complex. Standing too close to someone at the bus stop can be interpreted as intrusive; reading your spouse’s e-mail is a violation of privacy. If we give these interactions a thought in our daily life I think we add value to our community. I believe that a society where people comply to well-settled social norms is a better society than where people are indifferent to privacy or where privacy norms do not apply.

Trust is vital for civil society but at the same time very fragile and hard to keep. Still we need to preserve trust as hard as we can. We are together accountable for the social norms and how our society develops. We are able to embrace all the different types of privacies, not only corresponding with rights but also duties.

This is not a full-fledged account of privacy, but explains why the frustration has been so deep. Privacy means many things, and it both is static in the sense of referring to basic conditions of how we relate to others, but also fluid and dynamic, changing with technology and social norms.

## Chapter 6: Concluding Remarks

I opened this thesis with some remarks from leading privacy scholars describing how chaotic, complex and messy they find the subject of privacy. Not surprisingly many of them have set out to tidy the mess and organize the chaos. As a result we have a legion of definitions of privacy, usually accompanied by the view that privacy is best protected as a negative right. However, the social reality that privacy is reflecting is in itself messy and chaotic. Defining privacy as a right associated with the private sphere may seem to clean up the mess, but has the unfortunate consequence of omitting some important features of privacy.

The alternative framework I introduce is influenced by O'Neill's account of obligations. Defining privacy in relation to obligations highlights privacy as active rather than passive: we actively make privacy possible when we give space, leave people to be and respect information. Therefore we need to identify the obligations that correspond to privacy interests. The burden of privacy is not only placed on the person who shares information; it is just as much, or even more so, placed on the receiver. Privacy must be defined between the individuals, or between individuals and institutions, where the other has obligations to respect privacy. Furthermore, understanding privacy as an obligation underwrites the social aspect of worthwhile life: human flourishing does not depend on being alone from others but on being able to form different kinds of relationships with other people. For some of these relationships having privacy is a central value and for others it is less important. For these reasons privacy is importantly related to trust or trustworthiness—that we can trust others to comply with the rules or social conventions in place.

From this sketch of privacy as a social concept, we see that privacy is interpersonal. It is defined by interaction between the person who is enjoying privacy and the person or institution that has particular obligations. Social norms govern these interactions and define

these obligations. A society with hardly any privacy is a society of suspicion, where people think that information about them will be used to harm or shame them. In such a society we can have secrets but not privacy.

The literature on privacy is fairly recent, dating back to the late 19<sup>th</sup> century, and it seems as though the challenges to privacy become more complex every year. In my mind it is no coincidence that privacy has become more important in modern society. In rural society where people lived miles apart, privacy concerns were neither complex nor challenging, not because people had so much privacy but because there was not the complex social context for privacy. However, in dense societies, with crowded public spaces and advanced information technology sharing space and information becomes everyday practice. We form complex relationships with friends, neighbours, institutions and strangers. This gives a new context for privacy which becomes more and more important to value.

#### *Future directions*

I do not claim that I have introduced a fully developed theory of privacy; rather, I have outlined the features of a social understanding of privacy. What remains is to analyze the concept further in relation to different contexts and relationships. It is possible to develop this project in several different directions.

The most obvious next step is to analyse the obligations that arise from privacy in relation to different categories of obligations and to identify the ethical principles that connect different obligations. I only touched upon these issues in chapter 5 but more needs to be done. Each category of obligations merits further study especially specific imperfect and perfect obligations. There is also more to be done in relation to social community and different societies. Below I list few further topics.

1) *Specific imperfect obligations* arise within personal relationships, such as between friends, parents and lovers. These obligations need to be examined further in relation to trust and the detrimental effect it can have in intimate relationships when we are forced to reveal thoughts and feelings. To explore these issues it might be interesting to look at literature and films. Henry James' novel *The Golden Bowl* and Liv Ullman's film *Faithless* illustrate two different relationships and ways in which they deal with unfaithfulness. Comparing these works reveal the importance of trust in intimate conversations and the destructive role of distrust.

2) *Special perfect obligations*. The special perfect obligations require social structure and institutions. In this thesis there has been a focus on biobanks and genetic research. My discussion of biobanks in chapter 4 was mainly to illustrate the privacy challenges of modern technology and show the limitations of traditional accounts of privacy. However I did not explain how the social account of privacy can deal with these challenges. This remains to be done in a future study. Recent discussion within the literature on dynamic consent is also relevant here.

3) *Cultural differences*. In chapter 2 I discussed briefly the differences between the English and the Icelandic concept of privacy. One motivation for thinking about privacy as a social concept is rooted in my experience of thinking about privacy in two different languages, and the frustration in translating between them because of the different concepts. With different concepts we have different social norms and institutions. Therefore cultural and linguistic differences in relation to privacy merits much further study, with more examples from other cultures and languages.



4) *Privacy and community*. The relation between privacy and community is another direction to undertake further study on social privacy. I have only started analyzing privacy in relation to trust and community in chapter 5 but more needs to be done on this topic.

Still another way of examining the social aspect of privacy is to analyze it in relation to more general issues in moral and social philosophy so as to give it firmer philosophical grounds. Whatever direction this project will take in the future it is clear there are various ways to develop it further that hopefully will be as rich as the topic of privacy deserves.

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