

How to Respect the Will of Mentally Ill Persons

Thea Rehbock

Institute of Philosophy, Dresden University of Technology

In this article I oppose the current account of autonomy and informed consent in bioethics through criticising the four underlying prejudices of an objectivistic, dualistic, rationalistic and individualistic misunderstanding of the will. With special regard to the case of patients with dementia I argue for the thesis that the principle of autonomy, as moral principles in general, has unconditional and universal validity, but has to be applied differently in the face of specific situations and circumstances by means of the power of judgment (*Urteilkraft*). As the philosophical resp. anthropological basis of my argument I develop a broad understanding of the will in an Aristotelian and phenomenological sense. The practical consequences of my thesis consist in the ethical requirement of equal respect for the will of mentally ill patients.

Keywords: autonomy, informed consent, advance directives, dementia

1. The practical relevance of the topic: respect for the will of the patient

It is a widespread opinion in bioethics that the right to autonomy depends on certain mental capacities, or the so-called competence of the patient. It is, of course, reasonable not to fulfill the wishes of someone who is not able to understand and judge the preconditions, possible consequences, risks, or alternatives of her or his own decisions. It is also necessary to observe very carefully, especially in the case of mentally ill persons, what these persons are still able to do and to decide on their own, and to what extent they need assistance, surrogate decision making, and in special cases even paternalistic intervention. But it is, in my view, wrong to conclude from the fact of diminished or lacking mental capacities that the moral status of a person and the right to have one's will respected are diminished or lacking as well, according to the degree of the capacities. My thesis is that the moral status

Corresponding author's address: Thea Rehbock, Löwenstr. 5a, 01099 Dresden, Germany.
Email: theda.rehbock@t-online.de.

and the fundamental principles, rights and claims it implies are unconditionally valid and apply to any situation of human life, even after death.¹ But, of course, they apply in a different manner according to the special circumstances of the situation, including the mental state of the person concerned. According to Kant, moral principles have unconditional and universal validity based on non-empirical (a priori) grounds. But in order to apply them appropriately in the face of specific situations and circumstances we need “a power of judgment (*Urteilkraft*) sharpened by experience” (Kant 1997, 5). Thus, the obligation of respect for the autonomy and will of others is as valid in the case of a dead or demented person as it is in the case of living and mentally healthy persons. Only *how* the will can and has to be assessed and respected is different depending on empirical capacities, conditions, and circumstances of the concerned persons and their situation.

In the present paper I will argue for this thesis with special regard to the situation of persons suffering from dementia. Their mental abilities become continuously more limited and deranged. As with children, they are often not able to fully and adequately assess the risks and consequences of their decisions and actions. Therefore others, so-called surrogate decision makers, have to decide and act on their behalf and in their best interest. Nevertheless, the question arises whether demented persons who are assessed as “incompetent” cannot still express their will and their desires through their verbal or non-verbal (bodily) behavior; for example, through rejecting food and medication, pulling out feeding tubes, or through dancing, singing and playing. Their thus expressed will and desires may appear less rational, competent and reflected. They may appear incomprehensible and irrational in the view of their caregivers, or as inconsistent with their own former views and values. And it may be much more necessary to carefully interpret their behavior in order to grasp the will or desire they are expressing. But is there any reason why their will and desire should be less respected and taken into account? And should “incompetent” persons have less right to behave and decide irrationally or inconsistently than “competent” persons?

This question gains special—moral and legal—importance regarding the danger of wrongful paternalism and even violent behavior towards the persons suffering from mental disorder, as well as regarding the application of advance directives in the case of dementia. On the one hand, caregivers who only intend to protect the patient from harm or to care for their well-being are inclined to neglect and violate the will of the demented, for example, by compulsory feeding against their resistance in order to prevent starving and death, to constrain them and shut them up in order to prevent them from

¹ Argumentation for the status of the person and respect for the will of the departed can be found in (Rehbock 2012).

accidents, colds, and other dangers. On the other hand, it may be that the demented patient had, in the state of former competence before becoming demented, declared the wish to die in the case of severe dementia through foregoing treatment or even euthanasia insofar as it is a legal option. However, when actually starting to suffer from dementia, he or she does not seem unhappy with his or her situation at all. To the contrary, he or she seems to enjoy the remaining way of life, and even discovers new options for enjoying life which he or she despised or suppressed during earlier life. A famous current example in Germany is the case of the professor of rhetorics Walter Jens, who had publicly argued and fought for the legalization of active euthanasia and regarded dementia as incompatible with human dignity. Now that he himself has dementia, his wife, Inge Jens, who formerly shared his views and values regarding euthanasia and dementia, explains that he enjoys activities which he formerly despised, such as living on a farm and playing with animals. She experiences his present behavior as such an expression of a will to live that she would be unable to end his life according to his former wish. "Just as certain as we were then that we did not want to live like that, I know today that my husband does not want to die" (Jens 2009). Thus, the question arises whether such behavior can be understood as an expression of a volition suspending the former rational will articulated in an advance directive? Or can the former will only be suspended by an equally or almost equally competent decision as was required for the advance directive itself? Advance directives are regarded as a legal instrument which enables us to extend our autonomy to situations in which we lack the competence for autonomous decisions. For advance directives to be effective, it is required that they are drawn up in a state of competence. The same is true in the case of a suspension of an advance directive, even if it does not have to be made in written form. But can the obviously life-affirming behavior of the demented person be entirely ignored? Should it not be regarded as an expression of a will to live which some call a "natural will" (cf. Jox 2006, 2011)?

Several bioethicists deny that severely demented patients can express a will at all. It is widely argued that a will in the proper sense is only one which is based on rational grounds and can be linguistically communicated. What is called a "natural will" seems to be nothing more than desires aiming at immediate pleasure or at avoiding pain. Ronald Dworkin calls these desires "experiential interests" (Dworkin 1994, chapter 7). Dworkin maintains that the will and personality of an individual can only be expressed through "critical interests" (Dworkin 1994, chapter 7) which are based on a conscious and rational evaluation of one's life situation which the demented patient is incapable of any more. Only such a rational will seems to be a will in the strict sense which has to be respected according to the biomedical principle of re-

spect for autonomy. Following this position, there cannot be any collision between two contrary volitions in case of advance directives, but only a conflict between the former autonomous will and the actual obligation of care for the well-being of the dementia patient. In this conflict, the respect for the *former will* has priority over the obligation of care for the *actual well-being* of the patient. As Dworkin says: “If I decide, when I am competent, that it would be best for me not to remain alive in a seriously and permanently demented state, then a fiduciary could contradict me only by exercising an unacceptable form of moral paternalism” (Dworkin 1994, 231).

But is it right that the behavior of persons suffering from severe dementia cannot and should not be interpreted, acknowledged and respected as an expression of their will at all? I do not think so. This question or problem shows, as a good example, the importance of an accurate and differentiated philosophical analysis of underlying concepts for moral orientation and action. Dworkin’s position presupposes a concept of will and autonomy which is not totally wrong, but is too abstract and too narrow. As I intend to argue, the competence model of autonomy is based on at least four prejudices, which I call objectivistic, rationalistic, dualistic and individualistic. Because of these deficiencies, the underlying concept of the will neglects the bodily constitution of reason and language, and is therefore not suitable for adequately comprehending the situation of mentally ill humans.

2. Critique of prejudices

2.1 From objectivism to the unconditional respect for the person and the priority of communication

For the competence model of autonomy, in cases of doubt “the ability to perform a task” (Beauchamp and Childress 2009, 112) has to be tested according to defined standards. This is usually done with the help of clinical devices like “dementia rating scales” or “mental status exams”; “the assessment of decisional competence remains heavily a matter of clinical judgment” (Beauchamp and Childress 2009, 115). These “competence judgments” are supposed to have a “gatekeeping function” (Beauchamp and Childress 2009, 111) by distinguishing competent from incompetent persons resp. decisions. They imply “normative judgments” insofar as they “determine how to use the test to sort persons into the two classes of competent and incompetent, and, therefore, how persons ought to be or may permissibly be treated” (Beauchamp and Childress 2009, 112). In the case of incompetent persons, caregivers are obligated and entitled “to override that person’s decisions, to turn to informal surrogates for decision making, to ask the court to appoint a guardian to protect his or her interests, or to seek that person’s involuntary institutionalization” (Beauchamp and Childress 2009, 111). Thus the princi-

ple of autonomy has only “prima facie standing”; it does not apply to “persons who cannot act in a sufficiently autonomous manner” (Beauchamp and Childress 2009, 105). Whether it applies or not depends on clinical assessments of the mental abilities of persons.

Aside from a variety of problems which concern questions of the exact definition and the determination of criteria of competence, a more fundamental ethical problem consists in the underlying objectivistic perspective. From this perspective, the patient primarily appears as an object of medical diagnosis and treatment before being respected as a person with the right to determine and shape her own life. Opposing this standard model of autonomy, I want to argue for the primacy and unconditional validity of respect for the person and her will. Assessments of mental capacities may be necessary, and sometimes, in special cases of conflict, it may even be unavoidable to override the decision or to intervene in the behavior of a person who is not able to judge the consequences and risks of her decisions and actions. But paternalistic actions cannot be justified only on the basis of the principles of beneficence and non-maleficence. It can and must be assumed on the basis of good reasons and indications that these actions, while opposing the actual *statement* of the will, still do not contradict the *real will* itself. One has to be very careful, of course, in presupposing such a real will, which differs from the actual statement or expression of the will. Nevertheless this distinction is fundamental and necessary. Even in the case of clearly competent persons, it must always be possible to ask: “Are you sure? You say that you want to do or get X, but are you really willing X? Did you deliberate well?” If arguing with the other person is not possible, we must at least be very certain that he or she will or would consent to our paternalistic intervention. Furthermore, the competence assessments themselves are medical measurements which cannot be carried out against the persistent resistance of the patient—without violating his or her will and dignity—even if this resistance seems to be irrational and a manifestation of mental illness. Thus, the validity and applicability of the principle of autonomy cannot be dependent on competence judgments because this principle is the necessary basis and presupposition of those judgments as well as of any possible justification of paternalistic interventions.

As the statement of the will can and should not be identified with the will itself, respect for autonomy can and should not be identified with respect for the actual volitions or for the mental capability of making “autonomous choices”. Instead, respect for autonomy means respect for the person and her real will, which generally has to be the basic attitude towards other human beings even if they are unable to develop and communicate their will in a fully competent and rational manner. Understood in this way, this respect

serves as a guiding principle for our actions towards others in any situation, even after death, and all the more so in the state of coma or mental illness. The idea of surrogate decision making implies this orientation towards the will and the interest of the patient on behalf of whom one is deciding and acting. Any care or beneficence without respect for the will of the other person necessarily implies wrongful paternalism and disregarding the person and her dignity in the Kantian sense, since, for Kant, dignity means the unconditional worth of human beings as persons in contrast to mere things which may serve merely as means.

Using the Aristotelian distinction between *praxis* and *poiesis*, the psychiatrist and philosopher Wolfgang Blankenburg explains this fundamental difference of attitude in the following way. Towards mere things, we have an attitude of management and control through defining, categorizing, causally explaining, and eliminating of disorders. Towards humans, by contrast, the primary, unconditional interest has to be to understand and respect them as independent, autonomous beings, even in the case of severe mental disorder, and to help and enable them to live and master their own life and deficiencies. According to Blankenburg, freedom and autonomy are the guiding ideas of action towards mentally ill persons as well as healthy persons. In his *Prolegomena to a Psychopathology of Freedom*, he says: “The inner freedom of the human being is the secret, although unavoidable reference point, for every psychopathology and psychotherapy” (Blankenburg 1984, 174). In his view, the impressive progress of medicine in exploring and controlling mental disorders with the help of new technical means implies the danger that this technical-*poietic* view could come to dominate, or even override the personal perspective, and thereby promote the disregard of the person and the dignity of the patient.

Therefore, the question is not *if* the will of a person has to be respected, but only *how* this is to be done. One central requirement of respect consists in giving the highest priority to the *praxis* of communication with the person concerned. The definition, categorization, causal explanation, and elimination of disorders as well as clinical assessments of mental abilities may be necessary, but can only be justified on the condition of a communicative relation to the patient as a person. This means that those who care for patients are and necessarily remain involved themselves as personalities with their own emotions, values and judgments in the situation and cannot take up an entirely disengaged, clinical, impersonal standpoint of mere observation. This is true in the case of the “competent” as well as in the case of the “incompetent” patient.

Adequately informing the “competent” patient is a precondition for the validity of his or her informed consent and cannot be reduced to the imper-

sonal transfer of bare facts and information “*flowing* from one place to another” (Manson and O’Neill 2007, viii).² Instead it has to be decided which facts and information are adequate and relevant for the specific, individual situation and needs of the patient. Such a decision presupposes empathetic understanding and evaluation of this situation, putting oneself in the shoes of the other person, and adopting his or her position or perspective. This is only possible through personal communication and reflection on one’s own values, which may be different to the other’s values. Thus, information already implies evaluation and is already an essential part of the activity of caring, based on the principle of beneficence which is a necessary precondition for respecting and enabling the autonomy of the patient.

The same is all the more true for the clinical assessment of “incompetence”, which can and should never be a merely impersonal, disengaged, and descriptive statement. We must have reasons and indications for doubts about the mental health of others which can only appear in our communication with them. The more we fail to understand the behavior of the other person, the more it seems irrational to us, the more we doubt his or her “competence.” But we must always take into account the possibility that what seems irrational to us may be very rational from the perspective of the other person. It is never possible to get a fully objective account of the subjective standpoint and motivation of others. Therefore, communication has absolute priority over any form of objectification in our relations to others. It is false to say, as Peter F. Strawson and others do, that it is impossible to take on the “participant attitude” in the case of “mentally deranged”, “abnormal” or “incapacitated” people, and that instead only the “objective attitudes” of “intellectual understanding, management, treatment, and control” (Strawson 2008, 17) are adequate for dealing with them.³ It may, in special cases, be very difficult to understand the strange behavior of mentally ill persons but it is not impossible, as I will try to argue in the following.

How, then, can we communicate with these persons and how is it possible to ascribe a will to them which has to be respected? In order to un-

² In this book, Neil C. Manson and Onora O’Neill fundamentally criticize current approaches to informed consent in bioethics, which in their view tend to regard the information process between doctor and patient according to a misleading metaphor, as an impersonal quasi-technical “*transfer* or *transmission* of information from one *source* or *container* to another, through one *conduit* or *channel* or another” (Manson and O’Neill 2007, viii). These approaches thereby neglect the importance of the conditions, the manner, and the ethical requirements of successful communication.

³ “The participant attitude, and the personal reactive attitudes in general, tend to give place, and it is judged by the civilized should give place, to objective attitudes, just in so far as the agent is seen as excluded from ordinary adult human relationships by deep-rooted psychologically abnormality—or simply by being a child” (Strawson 2008, 11).

derstand this, we need a non-objectivistic as well as non-rationalistic and non-dualistic notion of the will. Bioethical theories usually identify the will with a mental event or activity, which is guided by rational grounds within the inner realm or consciousness of the person and articulated by linguistic communication. Opposing this account of the will I am going to defend a notion of the will which

- (1) cannot merely be assessed objectively, but has to be communicated personally;
- (2) cannot only be communicated by linguistic statements, but can be communicated by bodily behavior as well;
- (3) is not identical with the statement of the will or the actual volition but can contradict such a statement or volition, or can, in the case of the absence of any statements resp. volitions, be presumed on the basis of other indications and information;
- (4) is not reducible to the individual will which itself is only possible and understandable for others against the background of a “general will” that forms the general conceptual and bodily framework of human volition and pursuit.

After defending the priority of communication of the will in this section, I am going to argue for the necessity and equal validity of bodily communication of the will in the following section.

2.2 From rationalism and dualism to the bodily constitution of the will

The identification of the will with the rational will ignores the pre-rational, sensual-emotional conditions of the rational itself and produces a deep, unbridgeable gap between reason and sensuality, will and emotion, mind and body, language and corporeality. This problem becomes evident in opinions such as the opinion that the real will of the other person can only be found in his or her verbal messages, and that, if such messages are lacking, it is almost impossible to know the real will of others. In the case of mentally ill patients, it may, in special cases, seem to be doubtful if and how their bodily behavior could be interpreted as an expression of mental states at all. But can the will *in general* be identified with mental states which are hidden behind the bodily surface, so that only the subject him- or herself could know and communicate his or her will? Is it not obvious that I really *will* to do and achieve what I am actually doing and showing in my bodily behavior? It is of course possible that others' behavior may intentionally or unintentionally deceive

us. Kant provides the example of a man who is packing his luggage in order to make others believe that he is willing to leave his home, whereas he does not actually want to leave at all. But such acts of deceiving others through our behavior are possible only because we usually have no reason to doubt the will of others at all. The will is not a hidden cause of actions, but lies on the surface of their bodily behavior. In the actual behavior of persons, their will is often more clearly manifest than in declarations of intent, which may be mere wishes or even lies instead of volitions. If someone makes a promise but does not do anything to fulfill it, we have good reason to doubt that he or she was really willing to do what he or she promised to do. Sometimes we even surprise ourselves by our actual manner of action, which may be different from what we thought our will was.

It is not a new insight in the philosophical tradition to pronounce that the will is not a separate mental cause of the (bodily) act, and that the act is not an external effect and sign of a hidden mental state, as smoke may be an effect and sign of a non-visible fire. As has become or should have become clear since Descartes' times, there can be no causal relation at all between the mind and the body. Pain is manifest and present in expressive behavior; the will is manifest and present in visible action. It is only on this condition that it is possible to hide one's pain or real will through pretending something other than one is really feeling or willing. Wittgenstein expressed this insight by saying: "The will, if it shall not be a kind of wish, must be the action itself. It must not stop before the action" (Wittgenstein 1980, §615). Schopenhauer says: "The bodily action is nothing else than the objectified act of the will; that is, the will which became evident" (Schopenhauer 1974, §18).

In order to understand the underlying concept of the body and of behavior, it is helpful to refer to the phenomenological distinction between *Leib* and *Körper*; that is, between *being a body* and *having a body*. Whereas the "Körper", the body *we have*, is the mere physical body which can be an object of scientific investigation like any other physical thing in nature, the "Leib", the body *we are*, is the non-objectifiable medium and expression of mental life and of the person as the subject of life. According to this distinction, tears, for example, can be regarded as mere fluid flowing from the eyes, or as an expression of pain or grief. In a similar way, a movement of somebody's arm can be regarded only from the physical point of view as the mere movement of an object in space or, or from the personal point of view, as an intentional movement of the person, as an action of greeting or waving, for example. Usually we see the bodily expressed pain or action directly as pain or as a specific action unless we have reason to doubt that the person really feels, means or intends what her behavior shows. Thus, mental life is

not an isolated inner realm separate from the body; rather, it is present and manifest to others in the living body itself.

Understood as “Leib”, the body fulfills a double, ambivalent role. On the one hand, it separates us from others as singular individuals in space and time so that it is absolutely impossible exactly to perceive, think or feel what others perceive, think or feel. On the other hand, the body serves as mediator insofar as it enables us to comprehend and understand each other through bodily communication. Because our understanding of others is necessarily very limited and fragmentary, we always have to be careful not to falsely attribute an intention, motivation or will to others which they actually do not have. Such careless interpretations are often the reason for wrongful paternalistic interventions. But these obstacles and limits of understanding should not lead us to the mistaken view that we would not be able to understand others at all unless they tell us by means of linguistic statements what they feel, want or intend. Such statements may help, but they may require even more interpretation and may be even more uncertain than bodily behavior. The other person may deceive us and perhaps even herself about her real emotions, intentions or motives.

In order to shape a rational will with a much wider range in time and space, we need language, of course. But this is only possible on the basis of a pre-rational willing or volition in a much broader sense which we share as sensual-bodily creatures or animals with non-human living beings. In order to understand the *specific* nature of the *rational* will, it is necessary to presuppose a very broad sense of will, as Aristotle and, under newer conditions, Merleau-Ponty did. According to Aristotle, natural life in general has a teleological structure as a target-oriented—and following Merleau-Ponty, we could say, intentional—striving. Every living being strives after its own specific good. In the case of the human being, this good is a life led according to reason and virtue, but this is not possible at all without the basis of a pre-rational striving which humans share with non-human beings. In the case of humans, this striving (*orexis*) is non-rational but, unlike the vegetative functions of the body, it is guidable and manageable by reason. Insofar as the rational will (*bouleusis*) does not start from scratch, as a *creatio ex nihilo*, it has to be regarded as a natural striving which is specifically modified or qualified by purpose, deliberation and reason, and is possible through the means of language. The bodily constitution of the rational will means: The body we are, our “Leib”, is a mediator not only for our communication with other persons, it is first of all more generally a mediator for our relation to the world, or more precisely, as Merleau-Ponty says, it is our being towards the world (*être au monde*). This implies that our willing—as our perceiving, thinking or feeling—is necessarily related and open to the world

through our body. Our will—as our consciousness in general—would be helpless and non-existent without the concrete material of the will which comes about only through our sensual-bodily interaction with the world, from the very beginning of our existence.

If a child is crying and becomes quiet when fed or when comforted because of pain, it obviously *wanted* something to eat or *wanted* to be comforted. If the demented patient is happily playing with animals on a farm, an activity which, like the German professor of rhetoric Walter Jens, he despised in his former life, it is obvious that he is now willing to live in this way. By the means of language, the child will acquire the ability to communicate and describe its needs and desires, to reflect on and influence them on rational grounds and at times to suspend them accordingly. But this formation of a rational will is not possible unless it is shaped on the basis of the bodily-constituted willing and unless it is articulated through bodily expression. This is true even for the highest achievements of reason, science, and art. A thought, a number or an aesthetic idea are not identical with the spoken vibrations of air, the ink of the written letter or the chemical paints of a picture in the sense of physical matter (body as “Körper”); on the other hand, they cannot exist unless they are articulated in some kind of bodily expression (body as “Leib”). No one can conceive of these ideas and deal with them as possible objects of will and action in a merely spiritual manner. Thus, the body we are, the “Leib”, is necessarily linked to our mind and *vice versa*. But in order to understand how it is possible to ascribe a will to children as well as to demented persons, and also to animals or dead persons, we need to differentiate carefully between these different types of cases. And for this purpose we need to undertake a critical consideration of the fourth prejudice, the prejudice of individualism.

3. From individualism to the intersubjective constitution of the will

The view that we cannot know the will of another person unless she explicitly informs us is based on the prejudice of individualism insofar as it ignores the intersubjective constitution of body and language and thereby of mind and will. As phenomenology has shown, pre-rational sensuality is, from the very beginning, not entirely chaotic before it is structured by reason. Rather, according to our bodily constitution, the body itself is already structured and intentionally directed to the world and other persons in a very complex manner. Schopenhauer maintains that “the perfect suitability of the human and animal body for the human and animal will in general” is much more perfect than the “suitability of a tool for the will of its maker.” The “main appetites” of the will become manifest in different parts of the body: “teeth and

gullet are the objectified hunger; genitalia are the objectified sex drive; the grasping hands, the rapid feet correspond already more to the more mediate striving of the will which they represent” (Schopenhauer 1974, §20, 168). According to Merleau-Ponty, the living body (Leib) differs from the physical body (Körper), which may be an object of scientific investigation, insofar as “nous venons de découvrir jusque dans sa, fonction sexuelle’ une intentionnalité et un pouvoir de signification” (Merleau-Ponty 1945, 203). We do not understand mental disorders, Merleau-Ponty maintains, unless we appropriately understand the “normal” functioning of mind and body. We do not understand sexuality if we reduce it to mere biological functions of the body (Körper). Rather it is “une intentionnalité qui suit le mouvement de l’existence et qui fléchit avec elle” (Merleau-Ponty 1945, 183). Therefore we find—already in the realm of body and sensuality—“relations and attitudes” (Merleau-Ponty 1945, 185) as well as structure and order which in the rationalist philosophical tradition has been reserved for consciousness and reason. Language and reason extend the possibilities of human existence, but they do not create them. On the other hand, our bodily development as humans takes place, from the very beginning, in the cultural context of human society and language. Regarding the body only in the light of its biological functions is a secondary, reduced view of the body based on abstract thinking which blinds us to the cultural and social relations of sense and meaning which are present in the living body (Leib).

Thus, we do not find body and language as objective facts in the world; rather, we find ourselves in a world which is already constituted by commonly shared bodily and conceptual structures of communication and cultural life before we are able to develop an individual will. In order to develop an individual will, we must first to a high degree think, feel and will what others do. On this basis of a commonly shared body, we immediately understand the behavior of a crying child or a demented person like Walter Jens without previous reasoning and interpretation. We especially do not need any conclusion by analogy that others who behave similarly to us, in the case of pain, for example, must have similar experiences of pain that we do. Rather, we comprehend others’ behavior through a pre-rational understanding by means of the body (Leib). This means that we are intentionally related to the world through bodily communication and interaction with others, within a commonly shared and intricately structured framework, before we begin to shape an individual willing and personality.

Against this common background, we are able to understand the will of others in specific situations self-evidently, without any need to ask them. It is, for example, self-evident that we want to live, to eat, to breathe, to move freely, to shape our own life and so on. Life is an evaluative concept. Under

normal conditions, no one would come up with the idea of telling others that he or she does not want to live, to be free and so on. This is a kind of “general will” in the sense of Rousseau and Kant, although it is not only based on human reason but on our commonly shared bodily existence as well. It is only on this basis that we can understand, under special circumstances, the individual will to end one’s life. This individual will is a modification, variation or suspension of the commonly shared will to live. Thus, we are able to understand self-evidently the will of mentally ill persons as well as of children and animals, but we naturally draw specific distinctions between these different types of beings and situations too.

Unlike animals, children are (to be) regarded and treated as full members of the human society and language community, and thus as persons and subjects of rights from the very beginning, although their specific rights are distinct from the rights of adults.⁴ Kant says: “Children, as persons, have by their procreation an original innate (not acquired) right to the care of their parents until they are able to look after themselves, [...]. For the offspring is a *person*, [...]. So from a *practical point of view* it is a quite correct and even necessary idea to regard the act of procreation as one by which we have brought a person into the world without its consent and on our own initiative, for which deed the parents incur an obligation to make the child content with his condition so far as they can” (Kant 1996, 64). Doing this does not only mean “to feed and care for him [the child] but to educate him, to develop him both *pragmatically* [...] and *morally* [...]” (Kant 1996, 65). The specific will and corresponding right to be educated and developed can be ascribed to children from the very beginning without asking them. Only on this basis can the individual will and right to get a special kind of education be formed.

Like children—and unlike animals—mentally ill persons are (to be) regarded and treated as full members of the human society and language community and thus as persons and subjects of rights as well. But their specific situation, and therefore their specific will, is different. Although persons suffering from dementia, for example, often behave like children, their situation is very different from the situation of children. This cannot be understood if their situation is only grasped in terms of lost abilities. Instead, it has to be considered and comprehended in a broader anthropological framework, as well as in the personal biographic context of their individual life. As the possibility of becoming and being ill presupposes life in general, the possibility

⁴ In the case of animals, it would of course be necessary to distinguish between different kinds of animals with reference to their relation to humans. Domestic animals, for example, are (to be) regarded and treated more like members of human society than wild animals.

of becoming and being mentally ill presupposes mental life. This life and the person as the subject of this life may lose abilities, like memory, for example, and change seriously, but they do not disappear or become entirely different persons as some philosophers, such as Derik Parfit, and some bioethicists think.

We need the power of *imagination* and *free variation* (Husserl) of our familiar forms of life in order to understand others in their individual otherness, radical strangeness, craziness, or insanity, and to respect others even if we do not understand them at all. The more we are able to use these powers, the more we can see that a person, reason, and the will do not disappear in the state of mental illness, but only change. Wittgenstein says: “Madness must not be seen as an illness. Why not as a sudden—more or less sudden—change of character?” (Wittgenstein 1977, 106) Wittgenstein thinks in terms of a variation of the whole form and conceptual grammar of the individual existence instead of a disorder or lack of function which leads to the entire dissolution of reason, will and personhood. The remaining continuity of the person, in spite of perhaps severe and radical changes, cannot be found in objective facts or faculties such as the continuity of mental states or the functioning memory. Rather, it can only be understood and comprehended through communication and a narrative approach, that is, by telling the story of the person, as, for example, Inge Jens is telling the story of Walter Jens and his fate of suffering from dementia, losing capacities and suffering, on the one hand, and discovering new capacities and still enjoying life, on the other hand.

Michel Foucault emphasizes the ethical problem of the objectivist attitude toward mentally ill persons when he says: “Our society does not want to recognize itself in the sick person who is cast out or locked in; as soon as she diagnoses the disease she expels the sick person” (Foucault 1954, 75). Thus, discrimination and disregard of the person already happens on a theoretical level. Instead of regarding mentally ill persons through communication and interaction within a commonly shared framework and in the perspective of a personal, participant attitude, these persons are excluded by determining their deficiencies, strangeness and otherness through definition, categorization and causal explanation, through “management, treatment, and control” (Strawson 2008, 17) in the perspective of a merely objectivistic attitude. Because of their weakness, mentally ill persons are much more in danger of being treated paternalistically, excluded from society and disregarded. Therefore, under these conditions, the claim and obligation of respect for autonomy and the will does not require less, but even greater effort to understand and empathize with the person and her situation than in the case of “competent” persons.

Which consequences can be drawn from this conclusion for the special case of advance directives? Firstly, it can be questioned if the former “competent” will “not to remain alive in a seriously and permanently demented state” (Dworkin 1994, 231) can and should really have absolute priority over the actual bodily behavior expressing the will to live. It can even be questioned if the former will can and should be regarded as a *will* at all, or perhaps much more adequately as a mere wish regarding a future state of one’s own life, whereas the actual behavior expresses a will in the proper sense of the word. Schopenhauer says: “Decisions of the will (Willensbeschlüsse) regarding the future are mere deliberations of reason about what one is going to will some day, not real volitions: only the realization seals the decision, which heretofore remains a changeable purpose and exists only within reason, in abstracto. Only for reflection will and action are different: in reality they are one and the same” (Schopenhauer 1974, §18, 158). In the case of dementia, we cannot be sure what our future wishes and volitions would be. The future is, by its very nature, open, not only with regard to external events, but also in respect of the internal life of one’s mind. Furthermore, in the case of advance directives, the execution of the will or the fulfilling of one’s wishes is expected from others. They know our former wishes, but are confronted with our actual behavior which expresses our present will and may also contradict our former wishes and may therefore create irresolvable dilemmas and conflicts. This consideration may lead us to an insight into the limits of self-determination in the face of an open future and to a willingness to let us be determined by future possibilities of our outer as well as inner life, instead of attempting to entirely control them in advance.

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