Autonomy and professional responsibility in care for persons with intellectual disabilities

Herman P. Meininger

Research Fellow, Willem van den Bergh Chair for Ethics and Intellectual Disabilities, Vrije Universiteit, Amsterdam, the Netherlands

Abstract

The meaning of autonomy in the context of care for persons with intellectual disabilities is clarified by a sketch of different views of the *autos* implied in autonomy. The dominating concept of autonomy is largely orientated toward realization of the self into a sovereign individual and toward an emancipation that is aimed at freedom of choice and self determination. The concept of professional responsibility connected to this concept of autonomy has a technical-instrumental and contractual character. In an alternative view of the self as a 'story', authenticity and personal identity of both caregiver and care-receiver and their mutual relation are of central importance. Professional responsibility then takes on a dialogical character. This dialogical character includes, limits and transcends the valuable elements of the dominating concept of autonomy.

Keywords: autonomy, intellectual disability, professionalism, dialogue, life story, values.

Introduction

Policy documents issued by governments and health care organizations explicitly mention respect for personal autonomy as a central moral value and as a prerequisite for any treatment and guidance. However, in the care of persons with intellectual disabilities –

*Correspondence: Akkerweg 64, 3971 AC Driebergen, the Netherlands, e-mail: H.P.Meininger@th.vu.nl or hpmein@freeler.nl

and, for that matter, also in psychiatric care – the content and the applicability of the concept of autonomy is not always very clear. The change of paradigms in the definition of and support for persons with intellectual disabilities (Luckasson, 1992) has a major impact on the integration of persons with intellectual disabilities in society and on the way in which care for such persons is administered and organized. Persons with intellectual disabilities have demanded respect for their personal convictions and desires; they have been offered much more freedom to plan their own lives within the context of a growing range of options

in housing, work, community life and leisure. In many cases, however, it is not clear at all whether the persons involved have any understanding of the consequences of their decisions, especially of the potential drawbacks or even dangers these decisions may imply for themselves or for others. In such a case, is professional intervention equal to unjustified paternalistic interference in the autonomy of the client? Or should, on the contrary, the withholding of any professional intervention be considered as an act of irresponsible professional behaviour? Besides, there are many persons with intellectual disabilities who cannot themselves make their need of help known to others, who have no advocates to speak for them, and whose quality of life deteriorates into an unacceptable level without that help.

What is, in cases like these, the meaning of 'respect for autonomy'? It is important to have a clear understanding of this meaning, because it has immediate and forceful consequences for the perception of our professional responsibility regarding incidental decisions as well as the whole of our efforts in caring activities. In the care for persons with intellectual disabilities the usual definitions of autonomy, e.g. as 'the capacity of the individual to formulate and act upon plans and purposes which are self-determined' (Stainton, 1994, p. 27), do not always lead to a clear perception of the extent of professional responsibility.

In this article I will try to clarify the relationship between autonomy and professional responsibility by describing some background conceptions of the *autos*, the 'self' of autonomy. First, I will draw attention to some philosophical questions regarding the conception of persons with intellectual disabilities as autonomous subjects. Secondly, I will describe and analyse three conceptions of the self that can be discerned in discussions in philosophy and health care ethics. I will argue that different possible conceptions of autonomy are coherent with images of the human person that are implied in conceptions of the *autos*. Thirdly, I will sketch different types of professional responsibility that are connected with the described conceptions of the self and of autonomy. Finally, I will draw some conclusions regarding the practice of care.

Autonomy and persons with intellectual disabilities: an example from philosophy

The above indicated lack of clarity regarding the role of autonomy is not only caused by factual circumstances and (the lack of) capacities of the person with intellectual disabilities. It is deeply rooted in the way in which the existence of persons with intellectual disabilities is perceived (or even better: neglected) in western philosophical and theological tradition. Under the intriguing title 'Sind Geistigbehinderte amoralische Wesen?' (Are the mentally handicapped amoral creatures?) the German philosopher and pedagogue Franz Schönberger argues that persons with intellectual disabilities, seen in the light of the work of great philosophers as Plato, Aristotle, Kant and Hegel, appear as nonhumans, at best as children, that is: as human creatures who are on their way to being real humans. They are no actors, they are not *agens*, but only *patiens* (Schönberger, 1988; Goodey, 1992, 1994). From the view-point of these philosophies, persons with intellectual disabilities are creatures without reason, and thus without moral consciousness. Consequently, they cannot be autonomous. For the main presupposition of autonomy as a central moral value is the individual's capacity for active, independent, self-conscious and rational self-determination. Kant equated autonomous action with rational action, and rational action with moral action. Consequently, the question is whether we are able, as Schönberger states with severely intellectually disabled persons in mind, to '. . . consider creatures, which by their shape we recognize without any doubt as humans but who will not yet or ever speak competently, as human persons which can produce their own moral standards?'

At three major points Schönberger takes distance from the concept of autonomy that dominates European continental philosophy. First, he argues that autonomy is much more than critical, rational and reflexive self-determination. Also 'irrational' desires, wishes and motives have an important role. Of course, this has already been observed by David Hume, who indicated that passion and sentiment are the most important sources for the motivation of the individ-

ual. Secondly, Schönberger argues that the autonomy of a person cannot exclusively be dependent upon the 'activity' of wishing or willing. It may be necessary to derive the autonomy of a person from a careful and close reading (by others) of behaviour that at first sight seems strange or incomprehensible. Thirdly, Schönberger argues that the autonomy of a person always depends upon the relation to others, not only because everyone needs the support of others in the development and realization of one's desires, but also because sometimes persons depend upon others even for the expression of their desires (Gaedt, 1995).

The clash between the dominating concept of autonomy and the daily reality of persons with intellectual disabilities thus leads Schönberger to two different strategies. On the one hand, he tries to reformulate the concept of autonomy in such a way that virtually all humans are included. This is a philosophical and ethical strategy similar to the ones used by Stainton (1994), Widdershoven (1996) and Sohl *et al*., 1997). On the other hand, he refers to empirical research which demonstrates that persons with intellectual disabilities have much more communicative competencies than have been observed earlier. In terms of Schönberger: they are more *agens* than we have seen before, and thus they meet much better the anthropological criteria which are presupposed in the dominating concept of autonomy. This is a phenomenological and empirical strategy that has immediate consequences for pedagogical practice.

I think both strategies can be fruitful and are therefore necessary. Whatever one's concept of autonomy, it is always a moral obligation to do the utmost to understand the personal language of any person with intellectual disabilities. That is the important task pedagogues and psychologists have to set themselves. The considerations in this article, however, must be seen in the framework of a strategy of philosophical and ethical character.

First, however, I have to make one more important point about Schönberger's views. He does not make clear why the strange and incomprehensible behaviour of persons with severe intellectual disabilities produces particular moral standards. If that is the case, then why could the strange and incomprehen-

sible behaviour of animals or plants not also have an 'argumentative character' and produce *its* own moral standards? It seems to me that the status of people with intellectual disabilities as 'Normerzeuger' (producers of ethical norms) may not be based on the observation of behaviour and the reading of its possible meaning. There has to be another basis. That basis may be found in the recognition of the other as a self which has a claim to a unique authenticity. This authenticity is only revealed in relationship with others. It is not from behaviour, as such, that we may conclude the presence or absence of a self which is able to produces moral standards. It is in relating to the other *as a self* that behaviour receives its particular meaning. The self finds itself by the respect which is paid to its expression, that is: in the encounter with another self who is open to personal change by this expression (Meininger, 1998, pp. 217–251). From these considerations I conclude that any attempt to define the autonomy of persons with intellectual disabilities should not be orientated toward their behaviour, as such, but primarily toward a conception of the self.

Conceptions of the *autos*

To clarify possible conceptualizations of autonomy, I will distinguish three different conceptions of the *autos*. I designate these conceptions by the metaphors 'garden', 'way' and 'story'. In this section I will deal with the first two conceptions. They are close to each other and are firmly rooted in the liberal perspective of the image of the human person that dominates western societies. In the next section I will deal with the conception I designate by the metaphor of 'story'. The analysis of this conception may be considered as an effort to transcend the limitations which are pointed out in the first two conceptions.

The 'garden'

A garden is a closed locality. A territory which is owned by someone. The fence marks a closed space upon which outsiders may set foot exclusively with permission of the proprietor. In this image of the *autos* the self is independent and self-enclosed. This

self is its own ground and uses its reason and will as instrument of self-maintenance en self-realization. This is the image of the self which dominates modern philosophy (Dunne, 1995, pp. 137–139). This *autos* is originally an isolated being. Relations to other beings are a matter of choice, not of necessity. The choice to relate to others, or the choice to permit others to enter the private space of the self, is motivated by the possible contribution this choice can make to the self-realization of the subject. Relations thus consist in choices to enter into alliances which may be profitable to the maximal satisfaction of one's own interests, desires and wishes. The other only exists if and when (s)he may serve as an instrument in realizing my life-project. Nobody may enter into such a relationship with me that (s)he would be able to interpret for me where my interest or my 'good' might lie. In this conception a common good between the other and myself is not possible. If it exists, it is a merely accidental coincidence of individual interests. Therefore, relationships in which mutual interests are served usually have a fragmentary character and do not last very long. In the realm of the social, non-interference is the foremost principle of moral action. Self-realization is a matter of the closed and sovereign territory of the self.

Based on this conception of the self, autonomy is primarily interpreted as the absolute sovereignty of the individual. It is the type of autonomy that Charles Taylor sees illustrated in the work of authors like Allen Bloom and Christopher Lasch (Taylor, 1991, pp. 14–15). In his book *The Closing of the American Mind*, Bloom describes the mental climate amongst students in the eighties as an ongoing process of the closure of individuals into themselves and into a strictly individual pattern of values which in principle is not communicable and thus not accessible for others. Self and other are mutually impermeable. In interaction with others the individual is unable to discover or realize itself in new ways (Dunne, 1995, p. 139). Taylor denominates this attitude as the 'individualism of self-realization'. From the perspective of this model of the enclosed garden the passion of self-realization should be seen as the driving force behind an autonomy conceived as absolute sovereignty. In this conception the violation of territory, the intrusion into the sovereignty of the other, is the basic form of violence of one person against the other.

The 'way'

The metaphor of the 'way' refers to a conception of the *autos* as a continuing process to ever more self-determination. This dynamic image fits well into descriptions of human development as a process leading from dependence to independence, or descriptions of moral development as an exodus from irresponsible and immature 'Unmundigkeit' into fully self-responsible self-determination. Being human is seen as a way of continuous emancipation. The language of rights and of politics is an important element of this emancipation process. The son is autonomous if and when he can back out of the authority of his father. The nation is autonomous if it can make its own institutional and political arrangements without being subjected to the interference of other nations. The patient is autonomous if (s)he is able to restrict the power of the physician. The consumer is autonomous if (s)he has the legal instruments to abate the unlimited ambition of producers to make profit. These are all examples of processes of emancipation.

The self is continuously challenged to dissociate itself again and again from all those bonds which present themselves wholly or partially as relations of unequal power. This implies that the self must distance itself from the other. The other is seen primarily as the one who tries to exert power over me. The other is an opponent. In this conception of the *autos* an act of will is required which liberates from constraint and coercion. In this act the self manifests itself as equal to the other, an equality which finds expression in negotiation and contract. From the perspective of this conception of the self autonomy is primarily conceived as freedom: the freedom to determine one's own life. Heteronomy, the tutelage of others, is here considered to be the basic form of violence in human relations. Of course, the other who is my opponent may, under certain circumstances, become my sparring partner or even my ally in my process of emancipation into freedom. Nevertheless, persons are primarily seen as being involved in what

the Dutch philosopher Van der Wal called 'a great round game in which everyone is absorbed in getting his claims honored' (Van der Wal, 1996, p. 73).

The emancipatory character of this conception is a clear expression of the necessity of a right to autonomy in order to protect the weak from the unbridled and authoritarian self-realization of the strong. As in professional care relations the caregiver *per definitionem* is the stronger party, the right to autonomy and the respecting of that right must promote the view that this relation is guided by the priorities of the care-receiver rather than by those of the caregiver (Den Hartogh, 1997). Emancipation from the grip of the other can be fairly arranged on the basis of general principle of equality and justice. These principles warrant my being safeguarded against unwanted interference. They give me the rights that enable me to realize as much as possible my own preferences (Stainton, 1994, p. 110). This is the reason why all human relations are thought of as having primarily a juridical and litigant character. From this perspective, human relations are expressed in contracts and society is considered in terms of social contract.

Authenticity: a moral ideal and its degeneration

The two conceptions I described so far complement and reinforce one another. In the first conception, one person is an instrument of another person's striving toward 'getting what you want' (Brecher, 1998). Then the second conception is needed to enable the person to withdraw from the objectifying ('Verdinglichung') which is implied in the first conception of the self. There, the other is needed as an instrument of my self-realization. However, because I am more than an instrument of the other's self-deployment, I have to liberate myself from this heteronomy. I have to resist the violent act of annexation into the life project of the other.

Charles Taylor has pointed to the fact that a valuable and strong moral ideal operates in these conceptions. According to him both the conception of the *autos* in terms of self-realization and emancipation, and the conception of autonomy in terms of sovereignty and freedom, are based upon a moral ideal to

which he refers with the concept of 'authenticity'. The presupposition of this ideal is the existence of a definable and original way of being human that I am able to call *mine*. Authenticity then means being loyal to myself, that is: to that unique form of being human that I have come to recognize as mine.

Being able to experience this authenticity necessitates a certain degree of enclosure – a 'garden'. Being human is quite different from being a body between other bodies just because of the potential of the human being to be present to itself. It is indispensable to have your own territory and that is why limits that separate the self from the territory of other persons have to be defined very clearly. As it is stated in an old English saying: 'Good fences make good neighbours'. But the ambiguity of such a clear separation of territories is expressed in the Dutch saying: 'een kwa gebuur vereist een muur' (a bad neighbour requires a wall). In the Middle Ages *hortus conclusus* is one of the epitheta of the Virgin Mary and at the same time it symbolized the space in which a person – untouchable and unmoved by others – is enabled to search for wisdom and goodness, for a right relation to God and for fulfillment. Contrary to this conception, Luther's *cor incurvatus in se* (the heart that is orientated to itself) became the symbol of man going astray on the path of sin precisely because he is exclusively orientated toward himself and because he remains unmoved by the other, God or human. This self-enclosure of the self leads to a deadening of the self.

We should also keep in mind that the conception of the emancipating self to which I referred by the metaphor of the 'way' is in its own way deeply influenced by the moral ideal of authenticity. The possibility to experience the uniqueness of my own way of being human: that, of course, is what self-determination is all about.

However, Taylor argues that the conception of autonomy that is inherent to these conceptions of the *autos*, implies a degeneration of the deeper ideal of authenticity. His criticism regards several different but coherent aspects of conceptions of the self and of autonomy. His main argument, however, is aimed at the monological character of the self that is implied in conceptions of autonomy in terms of sovereignty

and freedom. He argues that this conception of self-sufficiency of the individual is a falsification of the moral ideal of authenticity. The reason is that in this conception, relations between human beings are fundamentally considered as secondary in relation to man's relation to himself. From a moral perspective, the influence of relations with others on the self should be seen as an interference which requires a thorough justification. For any interference contains the danger of paternalism, even if the relations are desired. That is why this interference and these relations should be surrounded by legal safeguards which regulate the claims of sovereignty and freedom of individuals with respect to one another. In these conceptions of the *autos* the relation to other human beings is not conceived as part and parcel to the structure of autonomy itself. Taylor's argument clearly coincides with Schönberger's search for a conception of autonomy which is anchored in the relation between self and other.

A second objection against the dominating conception of autonomy is aimed at the formal character of these conceptions. The envisaged freedom is primarily a 'freedom from', a negative freedom. The autonomy is about freedom of choice, as such. The substance of 'freedom to' is not discussed at all. Of course, this positive freedom and its substance are dependent upon negative freedom (Stainton, 1994, p. 16). However, the real meaning of a particular use of negative freedom – i.e. a choice – only manifests itself in comparison to the meaning of other possible choices. If all possible choices of individuals are equally meaningful, then any value is relative and any discussion about the substantial value of a particular choice is meaningless. A conception of autonomy in terms of sovereignty and freedom may be important, but as such it is without substance. Without this substance it remains formal and abstract. It is focused at self-realization and liberation from the unwanted influence of others. Then, however, the debate regarding the substance of the value orientation, upon the question as to what goods, ideals and purposes autonomy is used, is not any more the focus of ethical reflection. Then, the only thing we would need is a set of procedures to attain to a reasonable consensus. Then, the only important ethical question

regarding persons with intellectual disabilities would be the question of who may act as a substitute and which conditions and circumstances justify such a paternalism.

Now the question is whether the valuable ideal of authenticity can be retained without running into the pitfall of degeneration which Taylor indicates in the dominating ideal of the self and in the coherent conceptions of autonomy. In the following sketch of the self as 'story' I will attempt to accomplish this task.

The *autos* as 'story'

A third conception of the self can be described by means of the metaphor of the 'story'. From the perspective of this conception the *autos* manifests itself in a history, an intrigue, a plot. In a story the principal character is involved with others in finding the 'good life with and for others'. This implies that the other is also involved in the movement towards self-esteem which characterizes human existence. My movement towards self-esteem may be understood as a story about what I experience in others and about the full range of signification and meaning these encounters may have for me (Meininger, 1996). A story is the reconstruction of a movement towards self-esteem which goes by way of the other and his or her own movement towards self-esteem. This movement transcends categories like self interest, mutual interest or contract. It is about my involvement with others and about their involvement with me. It is about the 'sense' and the 'meaning' which may be derived from this involvement. Schönberger draws attention to the communicative content of the strange nonverbal behaviour of persons with severe intellectual disabilities. In doing so, he actually states a question about the meaning of certain ways of relating to the other and to the environment. This meaning remains undiscovered without the other or by distancing myself from the other. It only becomes manifest in encounter and involvement with the other and in the story which may be told about this encounter and this involvement. In this context, the Dutch philosopher Harry Kunneman speaks of 'narrative individuation' and attaches great value to the element

of bodily expression in this involvement (Kunneman, 1996, pp. 64, 79).

This argument does not imply that autonomy interpreted in terms of sovereignty and freedom is no longer morally relevant. What matters is that the conception of autonomy has been stripped of the halo of being the central value and the highest moral principle. Autonomy has been decentralized. This decentralizing is not just grounded in the fact that autonomy always has a situated character, but mainly because it is observed clearly that for the autonomy of a person, one cannot dispense with the other. The *autos* in this conception of autonomy does not exist without the recognition of its fellow human beings. In the conception of the self as 'story' the other is included in the structure of the self. It is by way of the other that I can become a self, *my*self.

This argument has been elaborated by George Agich in his work on autonomy in long-term care for aged persons suffering from dementia (Agich, 1993). The careful description of experience in this type of care leads him to criticize the liberal conception of autonomy which holds a central place in contemporary medical ethics. The limits of the principle of non-interference become visible when the care which has to be given extends to wide areas of life or sometimes to almost all aspects of life, as it is the case in long-term care for aged persons with dementia or for persons with severe intellectual disabilities. Then, according to Agich, autonomy has to be interpreted in terms of the whole of choices and relations, a continuum in the form of a life-style that develops dynamically through the adventures of life. Autonomy is about the spontaneous behaviour which is – without any calculation or reasoning – manifested by a person in the practical world of every day life. Following Agich, 'to be autonomous . . . does not require that one be able to manifest ideally rational and reflective free choice; what is required is to have a developed identity' (Agich, 1993, p. 102). A person is autonomous if (s)he acts in conformity with the identity (s)he has acquired in interaction with others and thus identifies with the things (s)he is doing (Widdershoven, 1996, pp. 112–118). Such a conception of autonomy does not only function at the intersections of life when important choices have to be made or

when an incidental crisis causes moral perplexities. It functions as an element of an 'every day ethics' which is orientated at daily routines and at the personal identity and the self-respect of both the care-receiver and the caregiver (Boggs, 1986). Autonomy, as Agich understands it, is the fruit of interactions between the person and her situation, between the person and other persons. 'Actual autonomy' thus is an element of a dynamic development of personal identity. This development does not only manifests itself as a growth toward independence of others, but also as a process of learning how to deal with the fundamental dependence upon others and with being involved in the life of others.

In this conception of the *autos* and of autonomy, dependence is not any more seen as the problematic reverse of the ideal of autonomy. Dependence may sometimes characterize a particular circumstance, but it is always an essential characteristic of all human beings. The important question for care-receivers and for caregivers is what the meaning of this dependence is for personal identity and self-respect. Autonomy in Agich's view necessarily implies a dialectic of human independence and dependence which he describes as interdependence (Agich, 1993, pp. 88–89). Dependence and independence should not be considered as complementary and thus mutually exclusive. Independence is embedded in dependence and dependence is embedded in independence. Actual autonomy, following Agich, is always embedded in care. Care is always embedded in the actual autonomy of both caregiver and care-receiver.

A clear understanding of 'actual autonomy' and its embeddedness in care may only be acquired by paying careful attention to the substance of the values and convictions of the persons which are involved in the care relation. In their being orientated to the other for both caregiver and care-receiver the important questions are: who do I love, for whom do I mean something, about whom do I care, to what cause do I devote myself, what are my ideals, who am I? These questions rest on the assumption that care is a relation in which both caregiver and care-receiver and their identities and moral characters are at stake. Because identity and moral character are decisive for the (im)possibility to listen to the other – the elder

with dementia or the intellectually disabled – in his or her authenticity, to help express this authenticity and to act in agreement with this authenticity.

As soon as I meet the other I am included in his or her story, as conversely the other is included in my story. Then, I am unable to be excluded from the adventures, the intricacies, the plot in the story of the other. Access to the authenticity, to the personal shape and lifestyle, and to the values and norms which are thereby expressed may only be found in a personal encounter. That brings us back to the moral ideal of authenticity as pictured by Taylor in contrast with the ideal of individual self-realization. Authenticity is a moral ideal with a fundamental dialogical character.

In a conception of the self as 'story', the other has a constitutive character. That is the first and most important difference with the two conceptions I analysed earlier. Here, the self is constituted by the other. The other is neither an opponent nor an instrument, but the other is the one to whom I owe my existence and who is a constitutive moment in that unique story which is mine. Of course, this role of the other may only be thought about in terms of reciprocity. For I, in turn, am a constitutive moment in the story of the other. My existence is more than being loyal to that unique form of existence which I call *my* way of being (Taylor, 1991, p. 29). As such, it is simultaneously an 'addressed' existence (Taylor, 1991, p. 35). It wants to be read as a letter or as a story. It demands to be understood in its substantial meaning. It invites the other to appropriation of and engagement in this meaning (Reinders, 1997, pp. 52–52). This is exactly why the relation between caregiver and care-receiver transcends the categories of contract, deliberation and informed consent. It is a relation which demands real dialogue and veritable encounter. This real dialogue may only be entered by posing the question: *who* questions and *who* answers? *Who* is the self which determines itself, and by whom or what is the substance of this self determined?

A second difference of the conception of the self as 'story' with the other conceptions of the *autos* may be found in the formal and abstract understanding of autonomy by which these conceptions are characterized. However, if we want to have a clear understanding of the unique substance of actual autonomy – which I described following Taylor by the concept of 'authenticity' – then we will have to start communicating about the convictions and views of 'the good life with and for others'. Being different, as such, is not important, but what matters is the implication of this difference in terms of meaning and in terms of the ethical destination of human beings described by Paul Ricoeur as 'the good life with and for others in just institutions' (Ricoeur, 1992).

The typical form of violence in the metaphor of the self as 'garden' was the intrusion of one territory. For the self as a 'way' heteronomy is the typical form of violence. In this understanding of the self as 'story', the characteristic form that violence between persons takes on, is anonymization. By anonymization I mean that disturbance of dialogue which is caused by a one-sided orientation toward the 'what', the so-called neutral, the negotiable, the measurable. This tends to make the 'who' of the involved persons invisible. Authoritarian tutelage anonymizes the care-receiver and is not interested in its authenticity. On the other hand, an attitude of total self-denial may lead to an form of anonymizing in which the authenticity of the caregiver is grossly neglected. Finally, the violence of anonymizing manifests itself in the reduction of self and others to mere consumers of care. This dehumanizing anonymity is caused by the fragmentation and commodification of care relations.

Professional responsibility

This description of different views of the *autos* and the analysis of the coherent conceptualizations of autonomy now enables me to determine different dimensions of professional responsibility.

If responsibility is conceptualized on the basis of a view of the self in terms of self-realization, then responsibility may exclusively mean responsibility for the self, for its own development and for the realization of its own aims and ideals. A responsibility for the other then only exists in terms of external laws which limit an unbridled execution of the self-responsibility. Therefore, responsibility for the other is mainly a forced responsibility. Very often it amounts to nothing more than the obligation not to

be a burden to others. In care relations, such a responsibility is determined by the character and the seriousness of the disturbance which disease and handicap mean to the process of self-realization. The character of this responsibility is distanced, fragmentary and short-termed. Metaphorically formulated: it aims at a quick and skilful repair of the hole in the fence of the self. The caregiver is responsible for his or her actions. Of course, skilful execution of professional actions may be part of the caregiver's own project of self-realization. It is also possible that the caregiver is solely interested in the economic or emotional gains which may be obtained by the execution of such actions. However, the substantial content of the aims and purposes of caregiver and care-receiver are not relevant. The only relevant requirement is that each person may develop his or her own project of self-realization. Thus, the ideal is that caregiver and care-receiver can be instruments of each other's process of self-development and self-realization. This sometimes leads to the problem that both partners tend to demand from the other a maximum contribution to their own project of self-realization, while at the same time the other tends to limit his or her contribution to the absolute necessary minimum.

If the *autos* is conceptualized in terms of emancipation, the responsibility of the caregiver is focused upon respect for the free choice of the care-receiver. This is the ethical framework in which a concept like 'informed consent' has central importance. The caregiver has the obligation to give to the care-receiver the information and the means to enable manifestation of self-determination, regardless of the aims and purposes of this self-determination. The wishes and the wants of the care-receiver are the all encompassing point of departure. The caregiver has the obligation to fulfil these wishes. In principle, this obligation is only limited by the availability of practical, technical and economic means. The execution is regulated by a system of quality and accuracy demands. Thus, the responsibility of the caregiver is not limited to a technically and methodically perfect execution of professional actions. It requires at the same time that these actions are carried out in the framework of a negotiated contract, according to a protocol which warrants a maximum of accuracy. Respect for auton-

omy then becomes manifested in a contract between caregiver and care-receiver. The preparations and the execution of the terms of this contract are regulated by legal measures which warrant the right of self-determination of the care-receiver. For instance, in care for persons with intellectual disabilities the envisaged accuracy is expressed in the requirement for a meticulous determination of the 'competence' or 'incompetence' of the person involved. 'Competence' should be respected and 'incompetence' should be compensated by adequate legal representation.

In the perspective of the *autos* as 'garden' or as 'way' the aims of professional practice are completely determined by the wants and wishes of the care-receiver (Reinders, 1994, p. 233). However, in the framework of a conception of the self as 'story' the dialogue on the substance and character of the aims of care is not marginalized by ascribing it totally to the realm of the private. This dialogue is the nucleus and the starting point of any professional responsibility. It is the heart of any relationship between caregivers and care-receivers (Gastmans *et al.*, 1998, p. 47). Professional responsibility thus has a fundamental dialogical character. This character manifests itself most clearly in long lasting caring relationships or when such a relationship has an extensive influence on the totality of present and future living (or dying) of a care-receiver. The answer to the substantial question about the aims of care may only be found by way of the story a person with intellectual disabilities tells about herself, or by way of the story others have read from her behaviour and her course of life. This dialogue requires a process of careful listening and interpreting. This is a process which transcends the practical and technical categories of summing up the wants and wishes of a care-receiver. That is why Schuurman in an article on the contribution of demand-driven care to the social integration of persons with intellectual disabilities makes a distinction between 'practical' and 'existential' demands (Schuurman, 1998, pp. 30–39).

Listening adequately to existential demands may for instance be done by a participating reconstruction of the life-story of a person with intellectual disabilities. This life-story should not primarily be heard in its historical-biographical dimension (what has hap-

pened?) but especially in its dimension of meaningfulness (what does that which has happened and that which is expected to happen mean to the person, and, how is that meaning expressed?). As I stated before, the life-story is always an 'addressed' story of how meaning has been found and ascribed (Monks & Frankenberg, 1995). This story may neither be found in the manifestation of the presence or the lack of some individual capacities of a person with intellectual disabilities, nor in the wants and wishes of this person. It may, however, be found in the meaningful bonds with others who are involved with this person and in a behaviour which has to be read carefully and in dialogue with the person with intellectual disabilities and those who are closely involved with her. This story can only be entered into by way of a committed dialogue on the substance of 'the good life with and for others'. Without that commitment, we can observe, describe and control many aspects of life, but we cannot understand anything about the authenticity of the care-receiver, let alone of ourselves. Seen in this perspective, professional responsibility amounts to much more and has a much more fundamental character than that which may be laid down in a contractual agreement or that which manifests itself 'in the market place of care' as a demand. 'Normative professionality' is characterized by a dialogue which envisages the authenticity of both caregiver and care-receiver (Kunneman, 1996, p. 81). What autonomy means in the life of an actual person has to be discovered in that dialogue. Autonomy cannot be determined by way of the formal, abstract and general criteria which are imposed by bureaucratic and technological orientated care policies.

Balance: the practice of care

To be clear: the above does not want to invite to a choice between one conception or another. Rather, I would argue that the conception of the *autos* as 'story' and of the understanding of autonomy in terms of identity should be the orienting framework in which self-realization and sovereignty on the one hand and emancipation and freedom on the other are embedded. For professional responsibility this would imply that the dialogical responsibility embraces, limits and

orients the technical-instrumental and contractual responsibility. This can be done by taking as a basic starting point the encounter between caregiver and care-receiver and the exchange of substantial meaning which gives shape to this encounter. The critical remarks I have made concerning the conceptions of the self as 'garden' and as 'way' do not alter the fact that sovereignty and freedom are valuable and important dimensions of the self. However, I have argued that their importance and value are limited. These limitations challenged me to develop a concept of dialogical professionality which transcends these limitations.

The possibility of the development of such a concept was found in a conception of the self in which authenticity is the dominant ideal and in which autonomy may be interpreted in terms of actual and substantial personal identity. Against this conception may be objected that it does not enter the question of power in human relations. That is exactly why continued attention should be given to aspects like sovereignty and freedom. The substantial meaning of sovereignty and freedom, however, may only be found in the wider framework of ideals and conceptions about the value and meaning of being human. If care for persons with intellectual disabilities is orientated one-sidedly at a limited understanding of autonomy, it runs the risk of neglecting the authenticity of both caregivers and care-receivers and thereby loss of contact with fundamental values of care as a human practice.

As to the consequences of these considerations for the practice of care I restrict myself to some short remarks. The descriptions and analyses of different conceptions of the self and of autonomy may lead to different practical forms of care giving. This is pertinent to the way in which care-receivers and their demands are perceived and interpreted. It also pertains to the ways in which care policies are formulated and implemented. And finally, it pertains to the ways in which in practical situations moral dilemmas between the well-known principles of 'respect for autonomy' and 'beneficence' are perceived and interpreted. In any case, responsible caregivers have repeatedly to become conscious of their own conceptualization of the orienting ideals and central values of their practice of care.

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