

## Research Article

### Personal Autonomy and Disability

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**Abstract:** This paper presents different approaches to the concept of personal autonomy in the disability context. It draws attention to the ways the requirements for “competent” bodies and autonomy of the “incarnate” subject affect the usual way of understanding the autonomy of people with disabilities, i.e. a higher degree of physical dependence may be perceived as a lower degree of autonomy.

**Keywords:** the body, independence, dependence

### Introduction

Reflections on the autonomy of people with severe disabilities are usually accompanied by ambivalence. This ambivalence is influenced by the fact that many people with disabilities, compared to healthy people, because of their health condition are more physically and/or mentally dependent on direct assistance or support of another person and/or adjustments of the environment. The degree of dependence is individual and related to the type, degree and progress of the disability, as well as the time of its origin, and duration. It is affected by personality, socio-spatial, and economical aspects, as well as other factors. A higher degree of dependency is usually perceived as a lower degree of personal autonomy. This ambivalence is also enhanced by some definitions of autonomy, where it is defined directly as the opposite of dependence (see below). Although every human being without exception is dependent on other people and environmental conditions, and the freedom to make his/her decisions and take actions is always relative, when thinking about autonomy, the aspect of physical self-sufficiency to be a requirement for the complete functioning of the body and mind is the aspect that is generally preferred. A number of routine and creative activities can be completed precisely and primarily due to their physicality. Being able to ensure one's needs using (their own) bodies (to stand up, sit, walk, eat, wash, read, write, talk, use the toilet, etc.) implies not only to be independent, but also not to be resigned to the mercy of others, their time and physical limits, moods, helpfulness, good will, paternalism or, conversely, lack of interest, etc. To have a fully functional body also means not to be an embarrassment, same not to burden or limit others, not to take away their capacity, etc. The moment of a physical change, when the freedom of the work(s) with one's own body is impaired or disabled, triggers psychological, social, economic and other changes, both in relation to its surroundings and oneself. It also reflects in the perception and definition of human autonomy, both with the people outside such a body and inside such a body.

### Dictatorship of a Complete Body

The body and its functioning is not just an essential prerequisite for being here and

now. Physicality takes upon itself, in terms of the sociological concept of a somatic-based society, social significance as well. According to Petrusek (2006, p.359), “the body and physicality are both not only the key conditions of our living in the world, but also a fundamental component of human identity.” According to the author, “Social, personal, and physical characteristics have the social meanings that are of different intensity and extent scale, and constitute substantial social differences, which are not always conscious” (Petrusek, 2006, p.359). Similarly, Lipovetsky points out the extreme demands that contemporary society places on the appearance and aesthetics of the body. A “young, slim, dynamic” dictate is based, according to Lipovetsky (1989, p.143), “On a narcissistic idea of success and performance, from which the value and the self-esteem of a man is inferred.” In addition, the dictatorship of the flawless body has reached proportions where “using a variety of methods and techniques we can transform our bodies based on different templates. ‘When scrolling through the shiny magazines, one has the feeling that they all actually tell one story - about ways to remake themselves, ranging from diets, and changing one’s appearance, through home interior to the restructuring of our own soul; all this often disguised with a challenge to be yourself (Stasiuk, sec. cited in Bauman, 2007, p.100).

The standards that attribute different social meanings and values to the body critically reflect social constructivist views on the body and physicality (see for example Foucault 1963). For example, Shildrick (2011, sec. cited in Kolářová 2012, p.16) notes, “An ideal standard in the context of modern Western discourse requires that our bodies are complete with no missing parts, so that they are predictable and under our control, and most importantly, an incarnate subject is autonomous”. Kolářová lists in a similar critical sense that “to be healthy, fit, qualified, and thus normal has become the uncontested prerequisite of the full life of a modern man as well as the condition of the recognition of his civil status and humanity” (Kolářová, 2012, p.17).

In the context of the aforementioned views of physicality and the need for complete and predictable bodies that we have under control and which as such are one of the expected attributes of personal autonomy, the contact with people with so-called incomplete or unpredictable bodies is confronted by the existence of diversity - differences. That, on one hand, attracts attention (fascination by a monster, the stare), on the other it creates separation, rejection or resistance. Partly this is a natural biological response to the new and unknown, and therefore to that which does not fit in the system of the so far ordinary individual experiences with non-disabled bodies, and partly it is about a defensive (usually unconscious) psychological response to the encounter with one’s own vulnerability ...what if it happened to me? ...What if it happened to one of my relatives...?

Requirements for competent bodies and the autonomy of an incarnate subject significantly affect the way the personal autonomy, hence the autonomy of people with disabilities is understood. In addition, a particular person with a different body is in this sense seen as the way too concrete and straightforward evidence of everyone’s physical or mental vulnerability, including a (so far) healthy body, which is 'despite its seemingly successful

independence susceptible to damage and breakdown (Shildrick 2011, sec. cited in Kolářová 2012, p.21). That damage and breakdown may yet come at any time, because, “The suddenness of these wounds, their irregularity and unsightly habit of coming every time from a different side - all this makes them unpredictable phenomena against which we are helpless” (Bauman, 2007, p.91).

Assuming that the so-called disabled body subconsciously reminds us of our own vulnerability, then in this sense, not everyone is able, face-to-face with a person with disabilities, to adequately process their contact with their own vulnerability. Despite some of the so-called more healthy ones being aware of the emotions (fear, uncertainty, panic, denial, resistance, etc.) they are feeling toward those so-called more disabled, they are not always aware, however, of the potential sources of these emotions stemming from unpredictable factors and, therefore, whenever possible, their own reality. While one person forces this potentiality out to less conscious layers of the psyche (It doesn't concern me. It cannot happen to me.) the other person actively fights out the encounter with his/her own vulnerability (e.g. denying the limits of one's body, putting a sharp boundary between oneself and those on the other side, etc.).

Either way, the way we see ourselves, and to what extent we are aware of the fragility of our own existence as well as the way we process the encounter with our own vulnerability is reflected in our perception of others. If the measure of all things is my view, where a sine qua non condition for the recognition of my autonomy is a self-sufficient body, then I can only accept with difficulty a different perspective on autonomy, where a self-sufficient body is not the necessary prerequisite.

The prevailing dictatorship of a complete body and the inability to cope with the existence of so-called incomplete bodies, as one of the age-old variants of human existence is, to some extent, a sign of a naive notion of the infinity of human possibilities, of the infinity of growth for Growth's sake. Bělohradský (2007, p.211) speaks of “the religion of the growth for Growth's sake.” Moreover, the era of a lack of ability to cope with even the existence of normal bodies has arrived. Plastic surgery today cannot only help, for example, to relieve body pain after heavy burns, but it can also, in the name of the so-called unlimited progress of human knowledge and the prospect of financial benefits, visually stop time, and therefore stop the aging of bodies (an old body seen as a mirror of finality). Anabolics and steroids, with the prospect of financial benefits, push the boundaries of artificial performance of top athletes; the natural human performance is no longer worthy of awards. Dolly, the sheep clone, started the next phase of so-called unlimited boundaries of human knowledge towards improving the ordinary or in the name of progress, only the fixing of incomplete bodies. In the name of progress and growth for Growth's sake, a memory of the natural order of things, which includes limits, is slowly disappearing, a pride is growing, and a humility which goes hand in hand with the understanding of ourselves and others is also gradually disappearing. Meeting with other, incomplete (and therefore 'disabled') bodies straightforwardly confronts everyone without exception with the finality of the frontiers, no matter whether individually human, or

with the finality of frontiers of scientific knowledge, which some people are unwilling, incapable, or unable to reconcile.

A biological normality discourse complicates recognition of autonomous competence of the bearers of “other”, distinct bodies. A mechanical perception of a normal and a normally functioning body as a competent body, able to satisfy the needs of a person, to which it belongs, produces the idea that a healthy person is, or should be, or has the potential to be autonomous. From there, it is only one step toward a preconceived notion of the contrary – an unhealthy body produces dependence, limited competencies, which is, in relation to the autonomy, usually perceived as contradictory. The mechanical concept of a normal body includes a conflict - imperative of a self-sufficient body is an internal conflict, and in relation to this study it raises questions: Can a person who cannot move independently and/or speak and/or eat independently, be autonomous? Can a person with a severe mental disability be autonomous? If so, to what extent? If not, why not?

Answers to these and other related issues will be very different depending on who is asking and who is answering, and they will reflect both the initial, necessarily diverse, socio-cultural context, and one’s own individual concept of autonomy. Perception and interpretation of personal autonomy is always related to a personal and cultural context.

### **Pain and Addiction**

Social and cultural perceptions about disability have been criticised for having neglected some important phenomena, which accompany disability (see for example Shakespeare, 2006). They include pain as an unmediated phenomenon. If pain is present, it usually changes one's view of the world. If the pain is persistent, it often changes even one’s values, priorities, and relationships to other people and to oneself. Someone who has been waking up in pain for a long time or permanently and is falling asleep in pain, as well as one who is close to such a person, address different priorities than someone who is struggling with the pain only temporarily or during an isolated episode. The pain aspect as one of the accompanying symptoms of some (but not all) types of disability is often left aside in social science debates on disability. On the contrary, it is in the centre of health science, natural, and theological debates. In the context of personal autonomy, pain is a subject of debates about the ethical dilemmas, such as the human right to die in dignity, the right to end one’s own life, and also sparks debate about the meaning of suffering that a permanent, deep pain brings.

Although pain accompanies some (not all) of the diseases, which partly cause a disability, it is usually automatically associated with disability. It is then often reflected in the perception of the image of people with disabilities as people who are sick, suffering (experiencing permanent suffering), powerless and weak. This tends to result in a fixation of the stereotype of disability = pain = dependence on treatment, and on others. In this case, the other body in the sense of 'helpless body' or 'painful body' may pose a latent sense of threat to a person’s own sense of autonomy and his/her projection on people with disabilities in

general. Non-dependence is not the same as autonomy.

## Dependence vs. Autonomy

Autonomy includes many dimensions of human existence - physical, mental, cultural, spiritual, social, economic, political, geographical, etc. Its bearer can be an individual – then we usually talk about personal autonomy, but also a group, organization, state or other entities. The concept of autonomy is ambiguous as are most concepts or terms in the social sciences.

The origin of the term derives from the Greek (from the Greek Autos - self, Nomos - law), where it originally referred to the institutional definition of city-states (independence, sovereignty) in order to be able to organize, and determine their own internal affairs independently of any other power. In this original form, the concept meant legitimization of the city-states for a specific action on their territory; it had political and legal importance. At the same time, the concept had a relatively simple and measurable content, because at that time it defined a mostly practical thing - autonomy was given to the state, which was able to provide – grant to itself and spread the word to others about – its own binding rules of life in its territory, act upon them, and had control over their compliance. The city-state that had failed (was not able) to provide them, was surrendered to a different power and lost its autonomy. For our further considerations of personal autonomy it is important that the original meaning of the concept relates to a group of people living in a certain territory. From now on, it is used in this sense, especially in connection with the autonomy of nations and states.

Issues with the concept started at the moment when the philosopher Immanuel Kant moved it from a group-political level, where the city-state had quite clear outlines of the content and order, to the individual-moral level as the opportunity and challenge for the man himself, e.g. a rational being, 'to determine and comply with the law, which he self-imposed' (Kant, 2011, p.18) in the 18th century. Kant continued the debate, raised already by Plato and Aristotle, on conflicting ethical and moral issues triggered by the autonomous will requirement. It is especially about the contradictions related to self-determination (will, wanting, freedom), and the legitimacy of enforcing the right to satisfy needs (liability, obligation) (see Kant, 2011; Aristotle, 2009; Plato, trans. 2003).

In the concept of man as a rational being, Kant saw not only the very person's ability to think rationally, but also and in particular that such a person based on rational consideration is able to determine right, i.e. moral rules for oneself and act on them. A prerequisite of man as a rational being is, according to Kant, not only that such person (1) rationally 'knows' what is "good" and "right" - and therefore moral, but he/she is also (with what is "good" and "right") internally in harmony with it (even if this was in conflict with his/her natural mentality), and that (3) according to this is capable to (responsibly, i.e. morally) act upon it. The reason thus becomes legislative for moral conduct in the person.

Kant's overturning of the autonomy concept from the social level (autonomy of the Greek city-states) to the individual level (personal autonomy) greatly complicated the originally clearly set outlines of the concept and measurability of its contents, because the order, from which the concept unfolded, was based on a human being and his/her abilities and skills to distinguish and determine what is Good' and what is Evil'.

A number of existing research and studies show that the interest in understanding the importance of autonomy continues to persist, and that the pursuit of its theoretical reflection has had a permanent basis in practice. Since the times of Kant and his predecessors, however, the concept has undergone, in pursuit of its theoretical definition, a significant change. At present, ambiguous meanings are ascribed to it, many having no ties to the original moral framework of the concept. From the theoretical perspective, meaning in the perspective of 'unordinary' language, this is a fairly controversial concept. Just like many other concepts in the social sciences, autonomy doesn't, and in fact cannot, even have a stable and clear meaning. Collopy (1988, sec. cited in Horowitz et al., 1991, p.29) speaks of the "conceptual plasticity" of this, by many even considered incomprehensible, concept and reaching the final definition of autonomy to be a "demonstrably impossible task". This plasticity is reflected in a series of attempts to define it in terms of diverse social science perspectives.

Contemporary philosophical thinking perceives personal autonomy generally as the ability of an individual to rationally act (Huber et al. 2005), or as self-management (Cole & Holstein, 1996), sometimes also in connection with a category of authenticity (Habermas, 2001; Ruppert, 2010). Psychology offers a view of personal autonomy as a category of quality - achieving autonomy is associated with the maturation of the personality and the ability of the autonomous personality "to resist social pressures in thinking and actions, make assessments based on one's personal standards independently from the approval of others, and break away from conventions, collective fears and convictions" (Sýkorová, 2007, p.74). Autonomy of the personality is defined from a psychological perspective as 'the extent to which the man is himself and can freely choose his/her activity, its location, time and type, or if necessary choose inaction" (Hartl & Hartlová, 2000, p.65). From the medical perspective, autonomy is generally defined as independence on help from others; it emphasizes the cognitive area in terms of decision-making abilities or freedom of choice (Huber et al., 2005).

From a sociological perspective, autonomy is associated with the freedom of the individual, with the social behaviour theory, socialization theory, as well as the theory of power. According to Sýkorová (2007, p.34), "Personal autonomy is usually identified with individual freedom, autonomy, sovereignty, self-control; it is sometimes viewed as free will or choice, as well as a decision-making process." The meaning of autonomy "is often acclimated to a functional, physical, attitudinal, emotional, and conflictual level. Personal autonomy is associated with privacy, dignity [...] personal integrity, and individual responsibility" (Sýkorová, as cited in Kalvach, Čeledová, Holmerová, Jiráček, Zavázalová, & Wija, 2011, p.34). From the perspective of systems theory, autonomy represents the ability of

the system to self-determination (Huber et al., 2005).

Schmidbauer (1994, p.35), for example, offers another definition, which defines personal autonomy as “self-determination, as opposed to dependence”, then Hartl and Hartlová (2010, p.65) as “autonomy, or independence, or functional autonomy.” Pichaud and Thareau (2007, p.97) define autonomy as “the ability to lead life according to one’s own rules. Being independent means to remain master of his/her own behaviour and way of life.” According to Ruppert (2010, p.84), “Real autonomy lies in the fact that one can unconditionally accept himself along with his/her own life reality and take full responsibility for his/her own life, whatever happens.”

A brief overview of attempts to define personal autonomy shows one of the reasons for a struggle with this concept - its definition depends on the individual value system, how a person thinks about autonomy and what kind of meaning he/she attaches (or doesn’t attach) to it. Despite the fact that it can be expected that there will be some common elements in people’s individual definitions of personal autonomy if they live together in a specific cultural context, ultimately, their definition will always be different. Some will emphasize in their definition independence, someone else responsibility, another one will place emphasis on authenticity, etc. This infinite definition pluralism of the personal autonomy concept is derived from disparate theoretical roots of the interpretative paradigm (especially hermeneutics, phenomenology, ethnomethodology, and social constructivism).

Although each of the above definitions explores personal autonomy from a different aspect and angle, the common denominator of most of them includes the two, at first glance, obvious aspects - freedom in the sense of making decisions about one’s own life and a capacity for intentional conduct. The selected contemporary definitions make it clear that most of them, unlike the original conception of Kant, lack emphasis on personal responsibility. Most listed definitions emphasize, in particular, the right to choose, the possibility to choose, to make decisions about one’s own life, as well as the right to maintain control over one’s life. Less emphasis, if any, is placed upon personal responsibility for one’s own choices, liability for one’s decisions and one’s actions, and duty to bear their consequences. However, it is two sides of the same coin - where there is the right and choice there should also be the duty and responsibility towards oneself and others. Either approach assumes awareness of boundaries, conscious recognition and respect of limits, which indiscriminately we all have, both the limits of our own body and mind, and the limits resulting from coexistence with others.

As cited by Sýkorová (Sýkorová, as cited in Kalvach et al., 2011, p.35), “Autonomy does not exist outside of social ties. [...] Social ties support autonomy, however at the same time, they restrict it; in the social space autonomy needs to be constantly negotiated in a reciprocal interaction of individuals. [...] Its achievement or sustainability is neither entirely certain, permanent, nor complete; it changes over time, depending on living conditions, social context, the nature and extent of the tasks with which people cope at the moment, on their

competencies and on the criteria which are used to assess them and their performance in society”. According to the author, “Seniors and people with disabilities are more likely to be exposed to the risk of weakening or even complete loss of autonomy” (Sýkorová, as cited in Kalvach et al., 2011, p.37).

Personal autonomy is a subject of interest to research published, for example, by authors such as Sýkorová (2004, 2007), Heathcote (2000), Quinnan (1997), Räikkä & Varelius (2013), etc. Most of their studies focus on autonomy within the context of old age. In terms of the relationship between autonomy and disability the works of the authors such as Crittenden (1990), Reindal (1999), Ells (2001), Wang & Dovidio (2001), Cardol, Jong & Ward (2002), Huber et al. (2005), Leipoldt (2010), Krhutová (2013), etc. are relevant here.

### **Toward a Personal Autonomy in the Context of the Disability**

Evans (sec. cited in Johnstone, 2001, p.61) points out the differences between the theoretical definition of the concepts of autonomy and dependence and their pragmatic interpretation: ‘Autonomy is a person's ability to live the life he/she wants. Independence means that you will not have to rely on other people. But it is not necessarily the same thing’. Similarly, Barnes points out that people with disabilities - as well as people without disabilities - often interpret independence within the framework of their selection and choices – “Independence does not mean that a person can do everything themselves, since no one can regardless of whether or not they are disable, but indicates that the person is able to take control over their own lives and choose what kind of life they are going to lead” (Barnes 1996, p.109). It is a thought process that does not depend entirely on physical abilities.

Empirical research shows, or more precisely confirms different definitions of autonomy by people with disabilities and professionals who are involved in solving their living conditions. For example, Ells (2001, p.599) argues that, “Many people with disabilities need assistance with the so-called tasks of everyday living (ADL) such as bathing, dressing, cooking, shopping, etc. Need for assistance is generally perceived by helping professionals as a proof of dependence, or the inability of a disabled person to make decisions about their lives”. “While the professionals tend to define independence of people with disabilities in terms of personal care activities (ADL), people with disabilities tend to define independence as the ability to have control over their life, and make decisions about them” (Reindal, 1999, p.357). Autonomy, in particular for professionals, often coincides with the capability to completely carry out activities of daily living often resulting in the conclusion that the clients, who are not self-sufficient, cannot be autonomous.

Sýkorová (Sýkorová, as cited in Kalvach et al., p.35) notes the impact of these completely different concepts of autonomy, where, “The interaction models based on expectations of incompetence, i.e. the anticipation of independence of a disabled person (even in situations, where they are reasonably self-sufficient), anticipation of their inability to decide, or anticipation of their inability to be responsible for their own decisions, results in



two effects: (1) on the side of a person with disability it is a weakening of their autonomy and the strengthening of their dependent behaviour, (2) on the side of others in their surroundings it is the strengthening of excessive protection and paternalism.”

In connection with the anticipation of incompetence, Sýkorová notes that, “It is the officials, specialists, professionals in helping professions, and last but not least, many relatives 'in the best interest' [...] of handicapped family members (or clients) who often define their needs for them, and more or less determine the extent and method of saturation of the disabled people's needs; they claim the right to control them, and supervise them” (Sýkorová, as cited in Kalvach et al., p.37). The notion of life with disabilities, showing just the “fatal consequences [...] of disability, which go hand in hand with the conclusions of the inevitable loss of personal autonomy,” seems, according to the author, “in the light of empirical evidence, unacceptable” (Sýkorová, as cited in Kalvach et al., 2011, p.37).

According to Pichaud and Thareau (2007, p.69), people represent the following personality types: (1) Autonomous and self-insufficient, (2) Autonomous, although self-insufficient, dependent more or less on others in some or most activities of daily living, (3) Self-sufficient, but non-autonomous, who satisfy their needs under the supervision of others, (4) Self-insufficient and non-autonomous, unable to satisfy the needs, or unable to decide what they need, or oblivious to what is good for them. If we look to that categorization from a greater distance, it is obvious that it doesn't just concern people with disabilities.

The conclusion of this paper shows the concept of personal autonomy by a woman who is completely or largely physically dependent on the daily assistance of others. Despite the fact that their views cannot be generalized, they are offering a view that is still hidden both to many professionals and amateurs:

Jana Hrdá, 61 years old, an expert in the field of social services, quadriplegic

“Being autonomous means to me - to be credible, authentic, and myself. In particular, this means, however – to be an adult in the sense that one can consider and evaluate important information using both reason and emotion in relation to themselves and others, then make a mature decision and assume responsibility for it. I am autonomous, although the extent of my physical dependence on others is complete, daily, and permanent. I see it as an objective matter related to my disability. Therefore I naturally accept assistance from others. I train social services assistants in a way that is acceptable not only for me but also for anyone who provides the assistance – because this is also about autonomy – if I admit it to myself, I admit it to the other person as well. The person who helps me is an equivalent full-fledged being, is unmistakable and unique. The tool for my autonomy is not 'this' person; the tool for my autonomy is 'what' this person does” (Krhutová, 2013, p.54).

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