

**Self-Determination: The Other Side of the Coin.
Reflections on a central but ambiguous term of the
German Disability Rights Movement**

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Abstract

Since its beginning, independent living has been a crucial demand of the German Disability Rights Movement. The call for independent living and the refusal of its opposite, heteronomy, is the focal point of its critique. Disabled people realized that the way in which disabled people are treated in terms of social policy and of personal care is a form of discrimination and not a natural outcome of their "fate". This insight enabled people with disabilities to claim independent living as a form of liberation. This article sheds light on a critical maxim of the German Disability Rights Movement, its merits and shortcomings, and uses the example of labor and employment as a means for examining its significance.

Keywords: German Disability Rights Movement, self-determination, independent living, workers with disabilities, employment and people with disabilities

Introduction

In German contexts, the idea of living independently outside of institutional control was framed by the term self-determination rather than by the term independent living. The objective, however, was the same in all countries: turning lives dependent on institutionalized care and welfare into lives of broadened opportunities and a wider range of choices. Whereas in the United States and Britain there has been much discussion and analysis of independent living concepts, in Germany the term was developed rather uncritically. Despite the presence of some critical voices concerning the unmitigated application of the concept, especially those of women with disabilities (Degener, 1992) there had been no serious discussion of the concept's strengths and limitations until a study by Anne Waldschmidt (1999).

During a 2003 summer institute entitled, "Sommerum Disability Studies in Deutschland — Behinderung neu denken!" ("Summer Institute Disability Studies — Re-Thinking Disability"), various German scholars, the authors included, presented their thoughts on the concept of self-determination (Siebert and Maskos, 2003). Based on the debates held during this workshop, this article discusses the various layers of meaning of the term self-determination and looks at its idealistic and realistic understandings. Our article, therefore, intends to spur new debates about the merits of the self-determination paradigm, as well as its potential to help move on basic, central disability rights goals.

After looking at heteronomy as a kind of backdrop against which the term self-determination should oppose, we discuss the various modes of understanding self-determination, using labor and employment as a critical example for the ambivalent implications of the call for self-determination. Since an independent life-style all too often boils down to the question of money and the distribution of funds in a welfare state, we argue that it is crucial to look at the vocational situation of persons with disabilities. The pressure to be able to perform in contemporary Western society, i.e. being gainfully employed, basically determines who can afford independent living options.

1. Heteronomy

The collective history of people with disabilities in Germany includes marginalization, invisibility and during the "Third Reich," systematic extermination. The history of marginalization and invisibility is not limited to Germany, but is in fact a reality for people with disabilities around the world. Still, the situation in Germany is somewhat unique in that the National Socialist's so-called T4 Program exposed people with disabilities to mass medical murder and mass forced sterilization (Klee, 1985). In addition, continuing the Nazis' systematic control of the disabled population, after World War II the structure of segregating medical and educational institutions was refined and broadened extensively. Therefore, for decades in Germany, there was almost no alternative or escape for people with disabilities from institutional care, and the nationwide net of medical registration had been tightly webbed.

Throughout the years, Germany's rehabilitation industry claimed to have a state-of-the-art infrastructure of disability care, all "for the good" of people with disabilities. But that meant that a majority of people with disabilities lived (and still lives) in conditions that were (and are) not nearly the same as those of the able bodied: Ghetto-like warehousing in institutions and homes, lack of personal assistance and denial of the right to choose one's own assistants, exploitation in sheltered workshops, and an inaccessible infrastructure are day-to-day discriminations. In Germany's institutions, when it comes to basic physical needs, rarely anyone is left out — as the ironical saying in the German Disability Rights Movement "*satt und sauber*" ("full and clean") points out. But apart from being "full and clean," there is no room for other basic human needs such as contact, occupation, culture, friendship, love and so on. And yet the plight of disabled people incarcerated within institutional walls, often against their will, continues: The number of placements of people with mental and physical disabilities into German institutions has been increasing continually, from 103,519 in 1991 to 160,346 in 2001, an increase of 53% (Kohrmann, 2005, p. 1).¹

The reality of disabled people's lives seems alien and frightening to most people. This seems to be both a cause and an effect of disability discrimination. Udo Sierck, co-founder of one of the first "Krüppelgruppe" (Cripples' Group) in Hamburg, stresses the societal and scientific continuities of patronizing behavior towards disabled people in his essay "Mifachtet — Ausgesondert — Vernichtet" (Disregarded, segregated, exterminated):

[...] the disparagement, segregation or physical extermination of cripples is not a phenomenon of an earlier past, but a continuing process, which is fueled to this day by the thinkers of their epochs, by clergymen and last but not least physicians or special education professionals. On the other side there are the cripples:

belittled to the status of an object, being put on the level of an animal, forced to curry favor with normality and pressed to despise their physical or mental difference — a history of the cripple as an accepted human being doesn't exist (Sierck, 1981, p. 27).²

The objectification of disabled people is the basis for their treatment as, at best, accepted — albeit not taken serious — persons, and, at worst, their reduction to the status of a "child of nature" or an economic burden. Historically, disabled people rarely appear as subjects with autonomous will and consciousness, but rather as objects that need to be managed effectively and judged through economic calculations. The freedom of disabled people under these circumstances generally means the freedom to choose details of their daily lives in an institution, sheltered workplace, or therapeutic clinic. Their rehabilitation is therefore achieved only when they can be useful to society, regardless of individual wishes and needs. People with disabilities are expected to live up to the standards of normalcy, and this alignment with societal expectations is equated with therapy. What is considered as exploitation for other, able-bodied workers is taken for "labor therapy" in the case of people with disabilities.

In a nutshell, many disabled people cannot organize their lives themselves; it is organized for them. Thus, the decision on what is meeting their needs is not regarded as being within their own competence. In spite of recent concessions made to the needs of those that rely on care providers, institutionalization still exists for disabled people, albeit outside of institutionalized settings. Heteronomy is still experienced by most disabled people today on a regular basis: the withdrawal of control over one's life conditions and having so-called experts and professionals decide about one's life.

2. Self-Determination — Definitions and Idealizations of a Paradigm

Only in the last few decades have disabled people succeeded in fighting their institutionalized oppression and in putting it into a political issue. Self-determination has always been a central expression in this fight for liberation from institutional dependency. Therefore upon first glance, the term appears to be a counter-expression to heteronomy: The power to control and to make choices should be laid back in the hands of disabled people; their expertise on their own lives should be acknowledged.

In light of the paradigm of self-determination, disability is not a mere unchangeable fate of the individual, but a process going on between the individual and its societal surroundings. Disability thus becomes a question of access and is no longer akin to inevitable suffering, condemning the "inflicted" to passivity. German Disability Rights Movement's slogans such as "I'm not disabled, I am being disabled" ("Ich bin nicht behindert, ich werde behindert") and book titles such as "The Mafia of Benefactors" ("Die Wohlthätermafia", Sierck, Radtke, 1989) show a move towards confident emancipation from heteronomy and institutionally organized care. The call for self-determination focuses on being accepted as an individual with a free will and a consciousness that is free to pursue his or her own interests.

In its form as a mere reply to the patronizing treatment of people with disabilities in the health and care system, the term is easily comprehensible. Not "they" decide, but "we ourselves," in other words: "nothing about us without us." But a second glance at the term shows its multi-layered meaning: on the one hand, the personal definitions of self-determination vary to a great extent; on the other hand, its ambiguity leaves unstable ground on which to formulate a generalizable definition. As a result, individualized definitions often switch back and forth between idealism and a presupposed limited demand on a self-determined life.

The ideal of self-determination can be understood as "absolute self-determination." In statements by disabled people on their personal meaning of self-determination, one often finds an ultimate wish for absolute self-determination, as well as a simultaneous recognition of its societal limits. Mr. A. for example, an interview partner of Anne Waldschmidt in her study entitled "Self-determination as a Construct," states

[...] I believe there is no such thing as absolute self-determination, either for disabled or for able-bodied people. Absolute self-determination would be to be able to do whatever you want to. That would be self-determination to me (Waldschmidt, 1999, p. 85).

Mr. A. sketches an ideal of self-determination, a definition of what self-determination could be if it was "perfect": to be able to do everything you want to do. But he also says that such a form of self-determination does not exist. We find similar statements in other personal definitions, since absolute self-determination would mean one's ability to set and follow his/her own goals and purposes, signifying a way of living on the grounds of an unlimited ability to make choices. But the ideal of free pursuit of personal purposes collides with the reality of its practical realization.

Debates on self-determination, therefore, are often grounded on the assumption that absolute self-determination doesn't exist. Ideal self-determination thus is not seen as a goal to be realized but rather as a utopian idea from which one has to be dissociated. "To do everything you want to" is impossible if only because it requires an unlimited amount of funds and resources to be fulfilled. This fact is a basic taken-for-granted assumption but also the precondition of the definitions of self-determination. Absolute self-determination therefore seems to be always an ideal, but an ideal that is an integral part of the practical realization of these ideas.

Therefore Gusti Steiner, who along with non-disabled journalist Ernst Klee, paved the way for the German Disability Rights Movement with groundbreaking writings on heteronomy and self-determination, defines self-determination this way:

Self-determination is not a principle of all or nothing or, worse, a synonym for self-realization. Self-determination means, to choose one option, in the absence of institutionalized constraints or paternalistic professionalism. This is the definition that is meant, re-historized and radicalized and that should be realized in the individual's life through personal assistance. No human being — whether disabled or not — is entirely self-determined (Steiner, 1999).

Steiner thus focuses on access when talking about self-determination. According to him, the expression can be distinguished from independence and autonomy:

Independence would be a life without the need of help of others. Autarchy, too, should be distinguished from self-determination, since autarchy stands for the lack of needs, economical independence, self-sufficiency and sovereignty. Self-determination should be understood in the sense of autonomy, meaning the right to take care of one's own business. Self-determination therefore can clearly be divided from heteronomy, being more or less a counter expression to heteronomy (Steiner, 1999).

Self-determination here is related to the sphere of personal assistance and the need for help. The consumers of personal assistance should decide for themselves when and what kind of assistance they need.

In other definitions of self-determination, the social and societal preconditions are taken for granted from the start as well. Considering these conditions is, however, important in order to clarify the conception's contemporary societal meaning, since the multitude of meanings associated with self-determination creates a fertile ground for misleading usages. The term is often misused for instance by institutions within the "disability business," against which it was once directed. For example, "self-determination," together with "integration," is repeatedly stated as a principle by health care institutions that work for and with disabled people — though, in fact, this doesn't change the content of their work. The Disability Rights Movement's radical understanding of the conception gets blurred this way, taking away the causticity of their critique of institutions; the term is being spoiled to a mere decoration of a heteronomical treatment. Gusti Steiner's comment:

They don't change the practice of segregating disabled people in homes and institutions but call the wardens 'assistants', disregarding the actual meaning of assistance (1999).

The concept of self-determination seems to be "hip," in arenas outside of the health care system as well, or rather their conceptual relatives: autonomy and self-responsibility, freedom and independence. What matters is the context of the term's utilization, as Anne Waldschmidt concludes in her study on everyday understandings of self-determination by disabled people:

The term self-determination, easy to be agreed upon at first glance, proves to be ambivalent at a closer look. It is open for very differing, contradicting contents, interpretations and practices. Instead of being a consistent, precisely defined constitutional concept it rather seems to be a formal construct whose specific meaning opens up only in relation to the specific practice stemming from it, which itself is dependent on societal and institutional contexts (Waldschmidt, 1999, p. 9).

In our view, the expression of self-determination can be seen in other dimensions than personal assistance or as a utopian idea. We think that self-determination can also be seen in a relationship to daily life in society and its principles. In light of an everyday meaning of self-determination, we see some limits to life imposed by self-determination itself — even though this might sound contradictory at first. A first hint at this paradox has been indicated already by the fact that absolute self-determination is an illusion. And it suggests the question of how it can be realized in society. What can self-determination mean if people encounter barriers to their actions all the time? And what are the grounds and the outcomes of self-determined decisions?

We now want to turn to the conditions of self-determined lives of disabled people and look at its foundations in today's society. As Gusti Steiner made clear in his statement that self-determination is always based on specific circumstances, we see a more salient, pragmatic meaning of self-determination. The flip side of his critique about the impossibility of absolute self-determination is grounded in the limits of actual societal conditions. An example for an actual and pragmatic understanding of the participation in societal life as a practice of self-determination is a quote of mainstreaming-theorist Bank-Mikkelsen:

Treat these people like you want to be treated yourself and you will. It is their right. Circumstances of life that already exist (quoted in Jacobs, 1993, p. 77).

3. Participation in Everyday Life: The Demands of Civil Subjectivity

With their call for self-determination, people with disabilities demand the same subject status that has been long granted to able-bodied citizens. There are many advantages to this undertaking: A legally equal subject is entitled to a lot more options in society, is able to pursue his or her interests and to fight discriminations. On the other side of the coin, the granting of a right also means the possibility of obligation. The legislator, granting the right, can demand specific commitments as well. This consequently means the obligation to fulfill the same tasks as other citizens. A civil subject therefore needs to submit to society's requirements. The acceptance of civil society's conditions is the price for having the civil subject's status. This is the real alternative to the "institutions of power" as anti-psychotherapy theorist Franco Basaglia (1978) called it.

Thus, disabled people have to pay a high price for their acknowledgment as subjects of modern society — a situation that Anne Waldschmidt calls a "Zwickmühle" (dilemma). The necessary liberation from patronizing structures like institutions and homes is endangered by the risks of an individualized society in which everybody has to take responsibility for her- or himself first. Anne Waldschmidt describes this as the

[...] autonomy of the individualized society [...] as a self-determination that is conceptualized less as a right of liberty but rather as an obligation. In neo-liberal modernity all individuals are left to themselves, they are successful in the short of personal responsibility. Only the fighter, the winner, the grantees of the self-made, tough person is in demand. Here, self-determination has a more disciplinarian character (Waldschmidt, 1999, p. 43).

Taking into account that the call for self-determination is going along with the demand for participation in societal life, this dilemma becomes obvious. Therefore, participation is the contextual frame of self-determined action, but at the same time its limitation. And the self-determined participation in societal life, if it is realized on a legal basis, can turn into an obligation as well. The *permission* to have a self-determined life thereby means to *have to* live self-determined. How this can be problematic becomes clear by looking at the conditions of a contemporary self-determined life. And the general questions connected to that are: What constitutes the normal everyday life of (able-bodied) people in contemporary Western society?

It is obvious at first glance that daily life consists of earning one's living, fulfilling personal needs and taking care of the things one aspires to. Thus, self-determination doesn't just mean the organization of daily living tasks, but also the gaining of necessary financial means. For disabled people this basically means the demand of a regular employment. And here we see one major problem of the unlimited demand for self-determination. We want to stress that by looking at the present sphere of employment.

4. Conditions of Contemporary Labor

Present German discourse about labor shows that modern employment is not exactly a pleasure for employees. The stakes for them are continually being raised and reformed; there are discussions about what can be expected from employees, as well as with what they are to cope. Modern employment proves to be no longer a life-long source of income and the flexibility of work hours and payment usually means less money earned for a second job workload. A lot of jobs don't even ensure basic subsistence, and therefore often a higher job becomes necessary. The "I-manager," regarding all of his/her character traits as potentials of value, the social and labor security net typically ensures a relatively secure basis of living, with or without a job; and usually there was only one job necessary — even though this didn't necessarily prevent huge differences in social stratification. In addition, the modern employee has to often event more than before: flexibility, cooperativeness, innovativeness, and resilience. She or he has to be both physically fit and show a personal commitment to the employer. And last but not least, she or he has to develop and internalize a positive stance towards all these demands.

German sociologists Hans-Jürgen Gess and Gerd-Günther Pongratz call this kind of citizen with the ability to sell her or his qualities that well the "I-manager" ("Ich-Unternehmer" or, as it is incorporated in the official language of a present German job-program, the "I-Corporation" ("Ich-AG") (Voss and Pongratz, 1998). The "I-manager" is basically characterized by a broad range of self-control and the obligation to rationalize her or his labor techniques. Additionally, an extension of these techniques of self to the sphere of privacy can be observed, the "corporatizing of life" ("Verbetrieblichung der Lebensführung") as Voss and Pongratz call it. In short: To live up to the constant demand of higher productivity, modern employees have to constantly motivate themselves to work, while controlling themselves and proving to be efficient. And moreover, they have to practice these principles also in private life. For instance, leisure and holiday time thereby can be set under the conditions of the current situation of the employer.

Eventually, the employees should dedicate themselves fully to their service in the corporation. Also, they must manage their inner personality with respect to all its contradicting emotions and the outside world. Even the self has to be used for success on the marketplace. The "I-manager," regarding all of his/her character traits as potentials of value, thereby relinquishes himself to the self-sufficient, flexible and universally useful means of labor, and is able to meet all demands. s/he understands his/her personality as a corporation to be managed, for instance by flexible time-management, ongoing education and qualification and self-motivation. s/he has an "inner account" of her strengths and weaknesses and continually holds "internal conferences," as Rolf Wabner (1997), German author of self-management books, puts it. His/her goal is individuality within competition, while simultaneously being a "team-player."

What does this mean for disabled employees? To cope with the demands of the "I-manager" will not make their already time-demanding life easier. Yet, there are some people that see them as prototypes, as the token model of the "I-manager." After all they are employers for their assistants and have to prove their organizational talent on a daily basis. And most of the ones having to rely on help are not to be socially competent "team players" just in order to get by. For employers of assistants these abilities are probably useful, but if these abilities are being utilized as preconditions for getting a job, the pressure rises for every one. For instance, in 2002, the German government issued the campaign "50.000 Jobs For The Severely Disabled," in which it discovered disabled people as role models for the flexible and always motivated employee.

The campaign created an image in which the able-bodied employee laid back in a well-webbed social net and only showed average job performances, while the disabled employees proved to be especially motivated in their performance. At least Michael Kretschmar, manager of an engineering company, says so in a brochure of the German secretary of labor: "Disabled people especially grasp their chances 120%. They want to prove their capability, because it is especially hard for them to find a job" (Bundesministerium für Arbeit und Sozialordnung, 2002, p. 28).

Disability as a competitive advantage? Getting people as trainees of corporate culture and motivation? If these notions help in disabling people with disabilities jobs they might be useful. Problematic, however, are the demands on disabled people's personalities and life styles that come with these notions, which they are expected to internalize.

Modern employees have to offer a direct financial gain to the company in order to find employment at all. This applies to disabled as well as to able-bodied employees. In which ways disabled people are exposed to those calculations — and as regular employees they are — is shown by a passage on integration services by Ralf Wetzell. This quote mirrors the side of the employer:

The starting point is: "Can a promise be produced that makes integration of people with disabilities possible or promotes it?" This question is necessary and legitimate from the point of view of integration services. But here, the position of the company is not taken into account. The answer to that question is still open from the point of view of the company, as long as integration cannot be transferred somehow to the sphere of competitive advantage and added value. So my first thesis is that: The motivation of a company is different if you turn the question upside down: "What kind of benefits regarding the building of lasting competitive advantages could a culture of integration bring to the company?" (Wetzell, 1998, p. 36).

The debate about disabled people as employees proves to be a debate about very fundamental aspects. Integration from an "interpersonal perspective" — and this is the crucial perspective where employment is concerned — always has to pay off for the company. Disabled employees, therefore, can be willing hands in two ways and thereby can set their hopes on employment: Either they show the same performance as their able-bodied colleagues, or even outdo them, or they prove themselves to be useful for the working atmosphere and thus bring about a more effective production. But what if disabled people cannot or do not want to live up to either standard? Since the decisive criterion at this point comes from the position of the employer, the disabled employee has to be profitable. This is the touchstone for the whole mainstreaming of disabled people within labor. Under these conditions, integration always has to pay off. Either directly: the person with a disability is a useful employee, or indirectly: she or he is creating a competitive advantage. This is stressed by a second quote from Ralf Wetzell:

If a participative work atmosphere is dominant, the staff agrees on basic values, accepts similar norms and so on, this can have a positive effect on quality and costs of a product, or entirely new products can be created. Culture therefore fundamentally influences the level of quality, the structure of costs as well as the ability of a corporation to innovate. Culture accordingly is an essential basis for the building and maintenance of competitive advantages and flexibility. [...] Integration could be an option for a company in order to raise awareness for the economic dilemmas. From this point on it is only a little step to the competitive advantage and from that on to the motivation to integrate (Wetzell, p. 37).

Whatever one's stance towards these conditions is — they are dominant in this society; they are the markers of the practice of self-determination of disabled people.

The debate on vocational integration doesn't at first appear to be central to the discussion about self-determination. But if one looks at the following, the context becomes clear: Self-determined action is always based on the given opportunities for action. And this is usually a question of finances. Both self-determination with the help of assistants in private daily life, and self-determined life without assistants depend on the amount of money one has at one's disposal. Thus, the discourse on self-determination raises the following questions: It is a political question of how much money disabled people are granted for assistant care. Is there some support, and if so, for whom and to what extent?

If one looks at present social cutbacks, not only in Germany but internationally, this doesn't seem like a promising perspective at all the moment. Expenses are being cut regionally and nationwide, especially the health system is being cutback and geared towards self-sufficiency and self-responsibility. Therefore, the state's priority is not social security for even on general welfare, but on keeping the economy fit for the world market and for global competition. Expenses in the social arena seem to be a contradiction to that interest, or, on the flip side, may prove to be useful for this goal. From that perspective, the financing of assistant care has to be legitimized in terms of economic necessity. In the case of doubt, this may mean that the necessary assistance will not be financed.

Thus, for many disabled people self-determination can signify an obligation to integrate into the job market, with all its merits and drawbacks, since their assistive needs need to be met by a sufficient financial background. And having sufficient assistance is often the foundation to escape institutional heteronomy at all. Disabled people's demand for "self-determination instead of welfare" additionally could be utilized practically as a political legitimization to cut back on welfare without reinvesting into personal assistant care. If self-determination is politically seen as a financial self-responsibility as well, it means less efficient and less social security and solidarity. And the alternative to institutionalized relations of power then is competition for the job. Generally spoken, self-determination can signify not only a way of liberation from control, but a pressure to turn external control inward, in order to create a competitive, self-reliant individual.

5. Conclusion

Considering what has been said, the German discourse reveals the multi-faceted nature of the term self-determination. In this paper we argued that it is important to reengage in the political debates about self-determination, while considering the contemporary social context in which self-determination and, accordingly, independence from patronizing institutions is a question of power and money. The Disability Rights Movement should therefore remain skeptical, especially where the will to prove oneself in today's society is concerned.

The call for being a full subject of civil society hasn't always been the main objective for the German Disability Rights Movement. Rather, in the beginning there was more resistance to the exclusion and segregation of disabled people. The movement's turn to legal issues and the attempt to bring about change within society's institutions was important. But now the movement's members have reached a point where proving to be capable of adjusting to the circumstances becomes more important than protesting against them. Opposition against integration now turns into a request for mainstreaming.

This, though, is not possible for some disabled people to the same extent as for the ones who are able to keep up with the pressure of the market. In the past few years, a growing critique of the German Disability Rights Movement has emerged regarding the existing hierarchy between disabled people, between the "fit disabled," who manage to get a job and to organize their lives by themselves and thereby live up to civil and normative standards, and those who despite broadened perspectives of self-determination don't manage to escape lives of dependency. A lot of disabled people feel as though they are being held in a two-class society, in which the larger responsibility, offered as a widened range of action through self-determination, feels rather as a burden on them than a new kind of freedom. As long as societal conditions aren't truly meeting the needs of disabled people, the conception of self-determination won't be able to get rid of its shadow of heteronomy.

Acknowledgements

The authors wish to thank Sara Vögt and Swantje Kobelt for their advice on translation.

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Endnotes

¹ The number of placements of elderly people in retirement homes is not included in this statistic. [Back to text](#)

² Unless otherwise noted, all translations are by Rebecca Maskos. [Back to text](#)