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Disabled People in Play. Toward an Existential and Differential Phenomenology of Moving with Dis-Ease

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ABSTRACT

Disability has become an increasingly important field of investment for modern welfare policy-visible in architecture for wheelchair users as well as in budgets for health care. This documents a gain in solidarity, but it implies also some challenges of practical and philosophical character. Play and games (of, for, and with disabled people) make these challenges bodily. These challenges will here be explored in three steps.

In the first step, we discover the paradoxes of equality and categorization, normalization and deviance in the understanding of disability. Ableism, a negative view on disability, is just around the corner. The Paralympic sports for disabled people make this visible. However, play with disabled people shows alternative ways. And it calls to our attention how little we know, so far, about how disabled people play.

The second step leads to an existential phenomenology of disablement. Sport and play make visible to what degree the building of "handicap" is a cultural achievement. All human beings are born disabled and finally die disabled—and inbetween they create hindrances to make life dis-eased. Dis-ease is a human condition.

However, and this is an important third step, disablement and dis-eased life are not just one, but highly differentiated. These differences are relevant for political practice and have to be recognized. Attention to differences opens up a differential phenomenology of disablement and of disabled people in play—as a basis for politics of recognition.

KEYWORDS

disability, Paralympic sports, play, phenomenology

At the Danish national festival of *folkelig* (popular) sport in June 2002 on the Baltic island of Bornholm, I had an experience that left me with wonder. From the tribune, I observed the arrangement of "dance across" unfolding on the grassy ground of the stadium. One could see folk dancers in their traditional Danish costumes, country dancers, square dancers, and line dancers, as well as ballroom dancers. Each group had its own style, accompanied by live music from the stage. Among these changing groups, there was a further one. What were they showing? As a spectator, one saw some more simple forms of dance in the

circle, couples moving in a somewhat clumsy way. What was the point of this performance? In some way, the performance of this group looked strange, and the spectators craned their necks. Until they – we – understood the point: These were disabled people dancing their part of the games.

One might ask whether the somewhat awkward movements of disabled dance were worth showing off in a festival of gymnastics. Did they deserve to be presented side by side with sharp rhythms, colorful costumes, and the elegant movements of the dancing athletes? And yet one could take just this experience home as a particular memory from the festival of people's sport – and this is what I did. The dance was telling a story of people's otherness in festivity – and yet of togetherness, which characterizes Danish folkelig sport. Disabled people are part of folkelig life, an important part. Their presence challenges the prevailing understanding of normality.

Welfare ableism in a critical perspective

Welfare society has increasingly become aware of the presence of disabled people. In architecture, the accessibility of buildings for wheelchair users has become standard. And in the statistics of health administration, expenses for disabled people make up a remarkable percentage. Welfare society wants to treat all citizens equally – this gives disabled people a particular significance.

However, equality implies a paradox. The intention to create equality by helping weaker and disabled groups in society has side effects that may contradict the humanitarian idea. It may even lead to stigmatization. Welfare policy means that resources are distributed toward certain target groups — and this distribution necessitates defining those who have the right to receive these resources. A definition is needed: Who deserves what sort of support because of which disability?

However, the definition of disability, as well as the definition of certain different disabilities, is problematic, for both epistemological and ethical reasons. "Definition"— de-fini-tion — is linguistically derived from the Latin *finis*. It is associated with a picture of little boxes, which are characterized by neat limits against each other. However, one cannot describe by strict limits what is historically changing or socio-culturally diverse.

The first was doubted already by Friedrich Nietzsche (1887, part 2: paragraph 13): "Only something which has no history can be defined". History in the world of disabilities is, on one hand, the biography of the human being, and there may be no strict line between the period when a person has obtained a disability and his or her previous life. On the cultural level, the history of knowledge states: Something that is regarded as disability today may not have be seen as such in earlier times, as, for instance, the attention deficit and hyperactivity disorder (ADHD). And vice versa, what once was seen as disability or disease, such as homosexuality, may by recognized as "normal" today. Furthermore, disability can culturally be different depending on whether one applies a medical view—also called impairment—or a social view, where one talks about barriers for participation in society.

Thus, the definition of disability is impossible from the perspective of knowledge. In addition, it is problematic in an ethical perspective. To be defined as disabled may be violating and detrimental. This wasseen from the perspective of today—obvious when those "others" in earlier times were called "idiots", which was both a medical term and a common sense invective, or "cripples" (crip, Danish *krøbling*, German *Krüppel*), "stupid", "retarded", or "feeble-minded" (German *Trottel* or *Depp*, Danish *sinke*). In the context of welfare thinking, a somewhat smoother and artificially elaborated terminology has spread, and one prefers to talk about disability, impairment, functional limitation (Danish *funktionshæmmet*), developmental limitation (Danish *udviklingshæmmet*), or special talent (German *anders begabt*). However, these new words either are euphemistic or can be indirectly discriminating — or both.

Against this linguistic smoothing, the German "movement of cripples" (*Krüppelbewegung*) rose in the 1970s, synchronically with the American Independent Living Movement. In the context of political activism, the "cripple" (*Krüppel*) received an undertone of oppositional group identity. The romantic comedy *Forrest*

Gump (1994), one of the most impressive and philosophical movies about disabled existence, played deliberately on terms like "idiot" and "cripple". "Stupid is as stupid does", as the "idiot" (Tom Hanks) says.

Another critical concept appeared beginning in the 1980s, the term ableism (also disableism or handicapism), denoting the assorting of human beings after their ability (whatever this may be). Ableism implies a negative view on the assumed "lack of ability" and is not so far from discrimination based on ability or disability. What does it mean to take human ability as measure for the differentiation of groups or categories? The challenge of ableism also casts light on the term of ageism, denoting in a similar way the aging of human beings with negative undertones. The terms of ableism and ageism had parallel careers in critical thinking during the past fifty years.

The common denominator of all these linguistic changes is an increasing doubt against normality and normalization. Is there any "normal" human being at all? Are all human beings in some way "deviant"? (Eichberg, 2011).

Paralympic sport for disabled people: Definition, classification, divisioning

Play is a particular indicator of the problem. Disabled people can play, just as non-disabled people play. However, society has developed sport as a particular form of (mostly competitive) play and games, and in this framework, the play and games of disabled people became sport for disabled people. In Denmark, this is organized in Dansk Handicap Idræts-Forbund (DHIF, Danish Federation for Disabled Sports), which includes the Paralympic Committee of Denmark. DHIF was founded in 1971 based on local associations, which had grown forth since the 1950s. As an umbrella organization, DHIF includes the Danish Deaf Sport Federation (DDI) and functions as a governing body under the Sports Confederation of Denmark (DIF), which is at the same time the National Olympic Committee for Denmark.

At the top level, Paralympic sport is mainly represented by the *Paralympic Games*. These had a precursor in competitions of World War II veterans with spinal cord injuries and the International Wheelchair Games linked to the Olympic Games of 1948. In 1960, the Games opened up to non-veterans. Since that time, the Paralympic Games have become a major sport event for athletes with certain allowed disabilities. There are ten of them: impaired muscle power, impaired passive range of movement, limb deficiency, leg length difference, short stature, hypertonia (spasticity), ataxia (a nervous dysfunction), athetosis (characterized by involuntary movements), vision impairment, and intellectual impairment (developmental disability). These categories are further broken down into classifications, which vary from sport to sport (Paralympic Games, n.d.).

Side by side with the Paralympics, *Deaflympics* are staged. They started as early as 1924 as the International Games for the Deaf, also called the World Silent Games. For participation, the athlete has to document a hearing loss of at least 55 decibels in his or her "better ear" and is not allowed to wear hearing aids or cochlear implants during the competition. The summer events consist of 14 individual sports and six team sports, and the Winter Games, five disciplines (Deaflympics, n.d.).

For people with intellectual disabilities, the *Special Olympics World Games* have been arranged since 1968. Intellectual disability is a term used when a person has certain limitations in cognitive functioning and skills, including communication, social, and self-care skills. These limitations can cause a child to develop and learn more slowly or differently than a typically developing child. Intellectual disability can happen any time before a child turns 18 years old, even before birth. Intellectual disability is the most common developmental disability. According to the American Association of Intellectual and Developmental Disabilities, one central criterion of intellectual disability is that the individual has an IQ below 70–75, and another is that the individual has significant limitations in two or more adaptive areas (skills that are needed to live, work, and play in the community, such as communication or self-care). Based on these measurements and classifications, children and adults competing in the Special Olympics are matched up according to their skill level and age. The so-called divisioning of the Special Olympics is motivated by a desire to make every

competition fair, competitive, exciting, and meaningful for both the athletes and the fans watching (Special Olympics, n.d.).

These events for disabled people are thus formed after the pattern of the Olympic Games. This implies that competition is central and that there are rules for inclusion, exclusion, classification, and segregation. "Divisioning" as an overall rule follows the definition of medical impairment, often measured by biological indicators. This is not so different from the Olympic separation between male and female sports. Gender testing, as it was practiced since the 1960s, was officially abolished in 1999 (by International Association of Athletics Federations) and 2000 (by International Olympic Committee) as being "invasive, humiliating, and potentially psychologically damaging" (Cole, 2005). The Special Olympics have also been criticized for segregation and for the promotion of prejudices and negative images.

And yet, in spite of those close relations between Olympics and Paralympics, one can also see an important difference. Olympic sport grew forth from a certain culture–from British sport culture, as it was adopted by French (Coubertinian) and European educational culture. Paralympic sport, in contrast, had its roots in medical thinking. One applies the medical paradigm of diagnosis, followed by levels of functioning in terms of impairments, and thus medically classifies the rich diversity of human ability.

A further event to compare with is the *World Masters Games*. This Olympic-type competition is designed for elderly people and officially intends to encourage young adults to continue competitive sport throughout life. It is especially popular with retired professional athletes and former Olympic competitors (World Masters Games, n.d.).

Common to all these quasi-Olympic sport arrangements is the paradoxical relation between normalization and segregation. The intention is to offer a "normal" pattern for sportive play, which is equal for all and gives people equal chances. The result is a more and more refined definition, classification, and separation of differently abled or disabled groups. But there is also a paradox the other way round: Without recognition of otherness, there is no equality of meeting the other.

Play with disabled people: Togetherness, accept, self-determination

In contrast to the para-Olympic sport events, play and games with disabled people can also be staged in quite another way. This is what happens at Legepark, the International Playground at Gerlev, Denmark. At this playground, traditional games have, since the 1990s, been the basis for play of and games with groups of all types-children, youngsters, adults, and elderly people. Disabled people were as a group involved into what is called *Handileg*, the word combining the Danish words *handicap* (disability) and *leg* (play). In cooperation with, among others, Filadelfia (an institution for disabled people) and with their professionals, play and games were arranged in order to promote a healthier lifestyle, social skills, and a better quality of life. The players were physically or intellectually handicapped, some with autism, Down syndrome, or epilepsy, and some 60–80 years old (Svendsen, 2012; Ahler, 2013).

The games ranged from lawn games,



run and catch,



and games of strength and tug of war,



to play of song and disguise



and traditional table games.



Source: Pictures with friendly permission from Lars Hazelton and Gerlev Legepark.

Furthermore, games that became especially popular among the disabled people were dance and song games (boogie-woogie, a popular Danish song-dance), and old traditional games like *Slå munk* ("Hit the munch", a skittle game), *Alle mine kyllinger* ("All my chickens", a game of song, run, and catch), and *Tyren i det røde hav* ("The bull in the Red Sea", a game of rope pulling and catching). These games are also funny for non-disabled people and make them likewise laugh like children. The games build community between all players, disabled or not, making them – among other things – go hand in hand and form circles of contact (Danish *rundkreds*). For the professionals, play was also training in acceptance of the limits for some disabled people, as some of these might reject participation in certain activities. And the disabled people began to express their own wishes and priorities among the games. Play opened the way for self-determination, i.e., for bodily democracy. The atmosphere that was created by play was festivity in the midst of every-day life.

All in all, what happened in Gerlev through the last years was play *with* disabled people rather than *for* disabled people. And it was play without classifying human beings. While Paralympic sport classifies after the premises of sport, play happened—or could happen—after the premises of the players.

Concerning play of disabled people, literature is lacking. How do disabled people play – when do they laugh, and what do they fear? How do they succeed in skill, and how do they cope with failure or

misfortune? Which game did they like, and which did they dislike? One of the playing women in Gerlev, for instance, had a mantra, which she repeated again and again in situations where she normally had become anxious: "We are just playing, are we?" What for her in another context might have become scary or terrifying became acceptable and even joyful in play. And I remember an event of traditional wrestling, where Scottish Backhold wrestling, which is based on pure tactile skill and rhythm, gave impressive advantage to a blind wrestler fighting a non-blind partner. When I told about this to a blind colleague of mine, she responded: This is just what I would like to do.

While the play of children has found a lot of attention, especially in the fields of psychology and pedagogics, observation and analytical study of the play of disabled people seems to be non-existent. The same is true for the play and games of elderly people. In conventional play studies, the one-sided focus on children's play has been the basis for a narrow understanding of play as a way of learning. This view, which has dominated large parts of play research, has been critically characterized as the "rhetoric of progress", as part of a typical modern mythology: "learning for future life" (Sutton-Smith, 1996). To understand the play of disabled people as well as the play of elderly people, this progressive and educational perspective is not at all convincing, however. Disabled people thus open up the broader philosophical question: How and why do human beings play?

Existential phenomenology: Disability as a human condition

The play of disabled people not only challenges our established understanding of play. It also casts light on our understanding of disability. The paradoxes between normalization and classification, between equality and recognition of otherness, demand a philosophical reflection.

Disability contrasts the ease and lightness of life. While policies of easement in welfare culture try to make people's life easier, the presence of disablement disturbs the picture. It calls to our attention that the human being is born disabled and dies disabled. And in-between, human beings develop culture, which is no less than an artificial creation of dis-ease, of building elaborate hindrances to be overcome. Peter Sloterdijk (2011, pp. 69–99) has recently drafted an ironical-poetical phenomenology of human existence as crippled existence. And indeed, at its core, culture creates difficulties of ease – enhancing dis-ease as human surplus value (Aggerholm & Jespersen, 2015).

Cultural dis-ease is especially expressed by play and sport. The word "handicap" is derived from practices of British competitive sport, from horseracing and golf, where special weights and other hindrances were introduced in order to make competition more equal and more thrilling (Hansen, in press). Also for foot racing, certain advantages and disadvantages were created (Kloeren, 1985, p. 255, 264). They opened up, on one hand, eccentric forms of entertainment, as in 18th century's cripple races, hopping races, and (female) smock races (Kloeren, 1985, pp. 251–252, 263, 267) and, on the other hand, in the world of modern sport, fraud and bluffing (Gotaas, 2009, pp. 114–128). Anyway, sport is a way to build artificial dis-ease.

On a more elementary level, in play, the ball is an ingenious cultural invention to make movement difficult. The ballplayer adds dis-ease to life: Can I handle this? And instead of just talking to each other in a rational, straight language, people sing. Instead of just walking from A to B, when there is need, people dance. All these are playful cultural creations of complicated movement and difficult life.

Artificial dis-ease paved the way toward sportive perfection. However, it would be one-sided to reduce human play and games to a striving toward perfection. While Olympic sport aims at the perfection of human movement, in play and games, one also experiences the opposite: the imperfection of the human body—and its pleasure. Much of the humor and laughter of play results from the experience that when casting, you miss the target; when pulling, you fall on your butt; when racing in a sack race, you stumble; when trying, you fail. Play presents the grotesque body, showing in a joyful way that the human being is imperfect (Bakhtin, 1968; Eichberg, 2013).

Play with imperfection is especially displayed in traditional folk dance. This dimension is often blurred by national-romantic and museum attempts to show the "correctness" of old dances illustrating identity by colorful precision. In real popular folk dance as social dance and *folkelig* entertainment, however, dancers will be able suddenly to lose the correct step, they can get out of rhythm, miss their partner, and even stumble–stumbling being a characteristic of the clown, the fool. The involuntary confusion and disarray of the dance gives the occasion to laugh about oneself. The imperfection of dance connects people in laughter and obviously contrasts the perfection of folkloristic museum display—it makes dance a play. Dance is not just easy—it is an arrangement of dis-ease.

The connection between play, disability, and dis-ease challenges the idea of easy play and easy life, which naïve play idealism as well as welfare ideology may regard as normal. But perfect health is impossible, and the human being is vulnerable by its existence. Disability is as normal as ability—and not just a mark of a social minority group or a label for a specific individual. And the connection between disability and normality is moreover related to death as an existential universal. We all die in the end. Death shows that the human being is limited, that it is imperfect (Shilling, 2012, ch. 8). Disability is not a reason for death, but a condition of life. Just as ability is a human condition (or striving), so too is disability.

Differential phenomenology

The existential view on disability implies, however, that one disability is not just like another. If there were just one overall human disability as such, the word "disability"— as well as the word "ability"— would not give meaning. There are deep differences — physically, psychically, socially, and culturally.

An Australian sociologist has reported an experience from a remote village of Papua New Guinea. Here she met three people with disabilities. A young man had received a brain injury at birth—he was loved and looked after by the whole village, including the children. A young woman had what we would call psychosis—she was believed to be possessed and people considered eye contact as dangerous, but she was allowed to take whatever food she needed from various cooking pots and clothes from washing lines, and she could sleep wherever she chose. A man in the thirties had received a spinal injury in his teens but had married and was father of five children — he lived in a hut with holes cut into the woven matting walls to allow him to observe the life in the village. He had once had a wheelchair, but it proved impractical in sandy soil and the wet climate. He was visited by his wife and children throughout the day and was carried when he needed to move somewhere. All three were integrated members of the village community without being labelled or ostracized, and yet they were treated differently (Cregan, 2012, pp. 62–63).

More fundamentally, there are deep differences between the disablement of the newborn baby, the disablement of old age, and the cultural dis-ease created as challenge by human culture, as well as between being deaf, being blind, being one-legged, and having Down syndrome. With the background of the existential disability of human beings, it is important to be aware of these differences. Disability does not exist in the singular.

And yet, awareness of disabilities, plural, does not mean to define them. It does not mean to create sorting lines and to place human beings in little boxes with labels. Definition and defined limits are surely needed for statistical epidemiology and for practical, especially financial, reasons of welfare investment (Bickenbach, 2014). The medical paradigm shows here to be useful, labeling and defining all sorts of impairments—and tending to dominate also in the social and political field. But on the level of humanist knowledge, we rather meet continua and processes than clear-cut "facts" of body or mind. Here, differential knowledge of human disabilities develops by comparing aspects of similarity and difference. In this respect, comparison is an alternative to definition.

Comparison is a procedure to make the differentiations of human abilities and disabilities clear. And play is an important indicator that can cast light on this diversity. A sensible differential phenomenology of play and games could help us to understand more deeply what it means to live in dis-ease.

Challenge of knowledge

What do we know—and how can we know – how and why disabled people are playing? These questions challenge our scholarly methods of knowledge. If one tries to ask intellectually disabled people about their play, this may give very little results. Report writing about play with disabled people – or, more precisely, play among all these differently disabled people – may easily fall into the trap of an abstract language of welfare policies (Ahler, 2013).

What is needed instead is a sensible phenomenology of disabled people in play. According to this differential phenomenology, the observer has to study living cases of human beings playing in community, differentiated after their respective disabilities. Studies of this character may lead to insights into the political paradoxes of the policy of disablement – insights into the inner contradictions of equality and difference.

Equality? Equality is the basis of human beings meeting in togetherness. However, there is no equality as such, no "objective" equality between human beings—but there is equality in relation to (...). And this is what matters.

Difference? If relational equality is translated into play and playful self-determination, then bodily democracy means living with differences. Some theorists have been fighting the idea of difference as being the root of discrimination. But no, differences between the Self and the Other are the root of politics of recognition. And, fundamentally, these multifarious differences question the one difference between the other and the norm.

Normality? In mainstream thinking, normal life is understood as life in health and without pain (Shilling, 2012, pp. 217–19). However, are illness, disease, and disability not normal? Not too long ago, science did not hesitate to characterize normality as being male, white, middle-class, or young or middle age, and healthy and heterosexual. This ethnocentrism has to some extent been broken down, and now female, non-white ethnic, lower-class, and elderly people are to some degree regarded as normal. And yet, the case of health and disability shows that the critique of normality has remained on the surface. There is no normality in human beings. And boxes like "disability" as such, as well as all those little boxes of measurable mental, intellectual, emotional, and physical "disabilities", are deeply problematic. Yes, we may need them for certain practical – administrative, welfare financial, epidemiological – reasons. But they remain social constructs, parceling the processes of human ability.

The human being is the measure of all things—this philosophical wisdom, expressed by Protagoras, we have inherited from ancient Greece. The sentence is still more challenging in our time, when medical science and welfare policy — useful as they are—try to measure, the other way round: human beings by things, by technical devices, by scales, by numbers, by medical categories of impairment. Disability as a human condition challenges the self-evidence of this practice. And play makes this challenge bodily.

In this perspective, reflection on disability is reflection on the human being in general. And in practice and on the basis of recognition, human beings can meet in difference. They can meet like in "dance across" on Bornholm, in *Handileg* in Gerley, and in play and games wherever in the world.

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