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Annerledes: Uten variasjon, ingen sivilisation

[Different: Without variation, no civilization].

Per Solvang
Aschehoug, Oslo
Universitetet i Bergen, (2002)

Per Solvang is a Professor of Sociology at the University of Bergen in Norway. In his research he has, among other things, analysed the situation of persons with differences and how these differences are experienced, interpreted and dealt with, both by the person who is different, as well as by professionals and welfare institutions. Solvang is a “class traveller”, that is his life-career has been one of upward social mobility. He was born in a small village in the northern part of Norway, and through his studies at a college in the north of Norway he became a university teacher and then a professor. He is also hairless. In his early teens he lost all his bodily hair due to a disease known as “alopecia universalis”. In his later teens he became a punk artist, leading a band that became controversial in the local media for writing song texts that were interpreted by some as nazi-influenced and satanic.

These three biographical hallmarks play an important role in this book he has written about the social meaning of being different. His experiences as a “class traveller”, as someone biologically different from others, and as a revolting punk musician are woven together with sociological theories and research, art and literature into a fascinating and multi-dimensional tapestry of great richness and stimulating, sometimes provocative ideas. The book is composed of several short chapters, each addressing different but related subjects. The relationship between the chapters is only partially of a logical nature, and equally as much an associative one.

Solvang’s basic perspective is social constructionism, where difference is seen as relative to its context. This point is driven home several times and with different

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examples. The changes in how we have looked upon baldness is illustrative as it relates directly to the author's own experience of his hairlessness. The fact that Malcom McLaren, a pioneer in the punk movement and manager of Sex Pistols, was possibly a person with undiagnosed Tourette's syndrome leads to the question of the usefulness of early diagnosis: How much creative variation is eliminated by neurological labels such as that? Being extremely tall is usually considered a defect in Norway, where the practice of attempts to halt the growth of young men at 1.95 meters is said to be widespread, whereas being tall in United States is a valued characteristic, something the author interprets in the light of the status of basketball and the resulting ideal of how manhood is thus created. But questions of what is different can only be understood in relation to how normality is constructed. What makes it normal to have an IQ of 100, a bodily height of under 1.95 centimeters for men and under 1.80 for women, or a penis that measures 12.9 centimeters? At the same time as we define limits for what is seen as exceptional, we automatically participate in the construction of what should be considered normal.

But the social constructivist position assumed by Solvang in this book is a moderate one. Variation, the stuff of which difference and deviance are created, is seen as given by nature, providing the raw material for social constructions. One of the basic themes of the book is how we evaluate the differences thus created. In modern societies one of the basic mechanisms for constructing difference is the welfare state and its need to allocate resources to those considered to have the greatest and most legitimate needs. For example, categories such as "disabled" developed out of the need to distinguish those worthy of public support from others who did not work but for less legitimate reasons. This is interpreted by the author as an example of a discourse of normalcy and deviance, one that is seen as closely linked to the distributive ambitions of the welfare state. The basic assumption here is that deviance is something negative, something that should be avoided or at least counteracted by different measures in order to "normalise" the deviant. This is obvious in prevention (and most notably, as the author points out, in preventive efforts based on prenatal diagnosis) and in rehabilitation, but also in what has been called "normalisation work" in places such as group homes for persons with intellectual disabilities.

One of the overriding ambitions of the book is to transcend the normalcy-deviance discourse by pointing to another way of evaluating difference. In order to do this, the author identifies a 'them-us' discourse, where difference is not negatively evaluated. The construction of difference is rather seen as something valuable and positive. One illustration of this is Deaf culture. This movement among deaf people articulates their situation not as one of persons deviating from normal standards of hearing, but as a specific culture based on its own (sign) language, with a common heritage of suppression and struggle to be accepted as a minority in ethnic terms, and striving for Deaf Power. This movement is based on viewing the culture based on sign language as something valuable and positive. The difference from such an approach and the traditional normalcy-deviance interpretation of deafness is illustrated by the debate concerning cochlear implants. These are mechanical devices that can be surgically implanted in deaf persons to help them experience

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sound. Part of the movement for Deaf culture has heavily opposed this practice, claiming that it is an imperialistic way of artificially alienating deaf persons from their culture.

Another movement that also serves to illustrate the them-us discourse and its break with traditional ways of viewing difference is the ampu-lovers movement that the author has identified on the internet. This movement is based on the celebration of amputated body parts, which is seen as something attractive and valuable, sometimes related to sexual attraction. This might seem absurd at first sight, but the author, who also reports from an international meeting of ampu-lovers, uses his knowledge to illustrate and pose questions about our changing views on body, body manipulation, and what is considered normal.

In his analysis of tendencies to positively value what in our taken-for-granted assumptions of deviancy have been previously negatively valued, Solvang is both empirical and normative. Empirically he claims to have identified tendencies that are in line with what several writers have described as typical of late modernity. Normatively he welcomes this development and articulates a vision of a society where variation is not only tolerated as a difference, but valued as such. This celebration of diversity is however not naïvely looked upon as unproblematic and, although mostly in passing, some of the problems attached to such an approach are acknowledged.

Solvang's use of an essay-style, that is his impressionistic and associative way of writing this book, is undoubtedly a strength. It takes the reader through a mixture of direct personal experiences, analyses of illustrative novels and films, research findings, and reflections based on everyday situations. In that way the book is far more stimulating than most research reports I have read (including those written by Per Solvang himself). But there is a price to be paid, at least from the perspective of a traditional academic such as myself. Many threads are left hanging, and important questions that are raised (explicitly by the author himself, or more implicit ones) are left unanswered. To pick just one example, I have some problems in combining the view of growing individualism in late modernity, which the author explicitly adheres to, and the basically collective nature of the diversity celebrating movements he refers to. The strong contra-cultural movement among the deaf, for example, leaves little freedom for deaf individuals to write their own biography based on dimensions of their choice, as described by several late-modernist writers. The celebration of diversity implies, as far as I can see, a strong commitment to the celebrated difference and is thus tying the individual to a categorical identity much in the same way as the distributive categories of the welfare state do. The author does acknowledge this problem, but does not take it any further.

At the same time it might be argued that this is not the kind of book where one should expect to find in-depth analysis of questions such as those that drive the text. I expect, and hope, that Solvang will return to all the interesting questions he has raised in due time. Until then I can certainly recommend this book to

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colleagues and students. With Solvang's book, Scandinavian disability studies (if there is such a thing) has both been challenged and taken a large step forward.

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I endringens tegn *[In the sign of change]*

Hilde Haualand
Oslo: Unipub forlag. (2002)

This book is the result of a research project about the accessibility of information for persons who are deaf. Besides a survey questionnaire to a large number of deaf persons, the project included qualitative interviews with four men and four women in two age groups (20-31 and 55+). In the book these interviews are analysed, an analysis which is theoretically driven. The stories told by the informants are put into a broader perspective, where their attitudes towards and ways of using information are examined, in the light of different discourses and characteristics of late modernity.

The analysis uses three different discourses, the first of which is a discourse about normality and deviance. Categorising something as deviant tends to automatically include being viewed as something negative, and something to be corrected. The understanding of deaf people as deviant has been institutionalised by medicine and pedagogy, both of which strive to diagnose, measure and correct deafness, with a focus on the limited ability to hear. The second discourse is one about equality and inequality (or sameness and differentness). This discourse is central to the Scandinavian welfare state, where material and measurable differences in a population are a central interest. Measurement of differences, for example through use of standard-of-living surveys, provides a basis for welfare state interventions, which typically address material and economical conditions, in hopes of correcting inequalities between groups and their larger populations. The third discourse is about 'them and us'. In this discourse difference is not negatively evaluated, but

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rather seen as something . positive. The movement among deaf people where deafness is interpreted in terms of culture and celebrated as a something valuable is an example.

Each one of these three discourses is related to a larger field of socially and culturally constructed meanings, values and understandings of social structure. Haualand writes about these fields as constructed or virtual worlds ("figureerte verdener"), in the sense that they are dynamic, that is, in a constant state of being. It is not the discourses in themselves that shape the language, actions and identity of individual actors, but rather their living in and through such constructed worlds. Haualand describes the relationship between such worlds and discourses as one where discourses are paths in a landscape of the constructed world. This landscape provides limits as to where the paths can be located, but at the same time these paths are part of the character of the landscape.

The discourse of normality and deviance in relation to deaf people is situated in a world constructed of sound. The virtual world of sound provides possible schemes for how to understand and evaluate sound and silence. Sound is not only seen as fundamental to human relations, but even constituting the true nature of such relationships. Haualand provides several examples to illustrate that language is linguistically penetrated by metaphors where hearing is actually equated with relationship. In this phonocentric landscape, viewing inability to hear as deviancy, in contrast to the normal, becomes the discursive path along which medicine and pedagogy contribute to the institutionalisation of deafness as individual, bodily and measurable deviancy.

In a constructed world where the discourse on equality and inequality becomes possible, the welfare state has a central place, where equality is the valued goal and where documented differences should be eliminated by political action. Haualand identifies a link between the normality-deviancy discourse and the equality-difference discourse in that both are based on assumptions that 'deviance' and 'inequality' are measurable, and objects for rational analysis and professional/political intervention. While the normality-deviancy discourse is focused on the body, the equality-difference discourse is focused on the distribution of material and economic resources in society.

The third discourse, that of 'them-us', relates to a world where the existence of a specific deaf community is constructed as essentially distinct from a hearing community. In the deaf community, sign language is interpreted as the basis for belonging to the culture, a culture with specific values and ways of experiencing and relating to the 'other' world of hearing. In contrast to the first two discourses discussed by Haualand, this discourse is based on positively valuing the difference thus created.

According to Haualand's analysis, access to information is typically examined in terms of the equality-inequality discourse. In other words, it is seen as something material, with an objective existence of its own, and as something that can and should be distributed equally among citizens. Access to information is seen as a

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prerequisite for participating in cultural and political activities and events, and is thus also seen as a democratic civil right.

This way of perceiving information is questioned in Haualand's analysis of the informants' stories. She argues that information is not a material good, that is to say something you have or not, but rather that information is always for someone, someone who is an active agent who can interpret and use the information according to his/her own wishes. This reflexive and individual way of understanding and processing information is strengthened in the era of late modernity.

Historically, the normality-deviance discourse preceded the equality-inequality discourse, and the them-us discourse developed through the reaction of deaf people to the normalising and integrating intentions that grew out of the equality-inequality discourse. Yet still today, all three of these discourses are present, and according to Haualand, form the experience and identities of deaf individuals. But they are also used by individuals to actively create their own biographies and identities. When Haualand's informants relate to information in different media, they are activating differently constructed worlds and discourses. The three discourses she uses are always present as lines, or paths, where the situation for deaf people can be interpreted. Her informants make active use of this in ways that depend a great deal on their own situations and contexts. Their individual reflexivity uses information for identity-work and positioning of oneself, in relation to both information and differently constructed worlds. The collage nature of media information are used to select and choose what is perceived and experienced as relevant.

I have tried to outline the basic analytic themes in this book. Yet is difficult in a book-review such as this to give a fair description of how these themes are used in the analysis of the informants' stories, because it is in the meeting with these stories that this book becomes very exciting. Haualand manages to portray her informants as reflexive and interesting individuals, and at the same time, she goes beyond what they are saying and concretely shows us the 'stuff' where their stories originate. In this way, she avoids being either too focused on the subjective world of the actors/informants, or over-emphasizing the determining power of the discourses she presents.

This book is based on a Masters thesis in anthropology, and in her preface Haualand informs us that she has 'popularised' some of the text, including that some discipline-specific parts have been excluded, and some discipline-specific/theoretical terms have been more explicitly explained. But even to me, a fairly experienced reader of social science texts, the chapter in this book presenting the theoretical and methodological approaches and tools was difficult to understand after a first reading. After having read the entire book, however, I better realised and understood her theoretical and methodological ambitions and intentions. In a book such as this, the methodological approaches and tools are perhaps best understood by seeing how they are actually used, rather than by way of a meta-description of what they are. This leads me to raising the question if

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Haualand's presentation of theory and method might be more understandable if it followed instead of preceded her analysis and discussion. After all, a format where theory and method come first is an artefact of the typical positivistic text, where analysis is less dynamic and less process-oriented.

I enjoyed reading and learning from this book. For those who will follow my recommendation to read it, I suggest skipping Chapter Two the first time around, and returning to it after having finished the rest of the book.

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Vardagslivets arenor. Om människor med utvecklingsstörning, deras vardag och sociala liv.

[The arenas of everyday life. About the daily and social lives of people with intellectual disabilities.]

Bibbi Ringsby Jansson. Doctoral dissertation.
Göteborg University, Department of Social Work,
Report series 2002:3 ISBN 91-86786-36-4 (SEK 170, 291 pages)

The doctorate dissertation of Bibbi Ringsby Jansson is a study of Swedish group homes for people with intellectual disabilities. The dissertation is about accommodation, but as the title suggests, the focus is on the social relations and everyday life of the residents. In separate chapters she analyses the use and function of a) the private apartment, b) the communal/staff rooms, c) the residential area/neighbourhood, and d) the community at large. The main and in my opinion important contribution of the book is related to the emphasis on spatial organisation and the role of "weak ties" in the everyday life of people with mild to moderate intellectual disabilities. These analytical tools appear helpful in order to make clear some aspects of the people's social and everyday life that is usually disregarded.

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The book is a report from an empirical study that took place in three group homes. Albeit different, the group homes all represent a new type of accommodation emerging in Sweden in the 1990s: group homes where the boundary to other housing is less distinct than usual. Such group homes may for instance consist of six to eight apartments dispersed in a housing project or residential quarter of maybe thirty to fifty flats. One apartment serves as staff location and communal rooms. The rest of the “group home” consists of single person households/ flats. Apart from that the area consists of people usually living in such an area. The three group homes included in Jansson’s study were situated in rather different residential areas, both with regard to characteristics and size of the population, physical and architectural appearance, and proximity to city centre and other places where people gather. The empirical data include about 470 hours of observations and informal conversations, and formal interviews with 18 (of 22) residents and 15 care workers. None of the residents had severe intellectual disabilities.

Studies of the social network of people with intellectual disabilities tend to have the perspective of social inclusion, and especially paying attention to the informal parts of the network such as friendships, community relations etc. It can be argued that the research has furthered a normative image of what a social network should look like (cf. Söder 1993), an image which adheres to a fairly “young-middle-class” ideal. Thus relations to for example family and to staff have been disregarded. Bibbi Jansson’s dissertation widens the perspective even further by bringing in the importance of “weak ties”. “Weak ties” refers to people we know, but where the contact is limited, often superficial and usually brief. It is people we encounter, but far from intimate friends or close family. The woman one meets a couple of times a week because she works at the grocery store may be an example, the guy at the local pizzeria another. The importance of weak ties is not about each and every person, but the whole complex network of such relations. And as Jansson’s analysis suggests, weak ties may be of significant importance to a substantial group of people with intellectual disabilities, both as social relations and as a means for making their way in the community.

Within the limits of a brief review, it is of course impossible to do a book of more than 250 pages justice, especially since many of the empirical descriptions are about variation rather than uniformity. The people studied by Jansson use their spatial environment in different ways. This applies to all the studied areas; the apartment, the communal rooms, the residential area and the local community. She describes people who use their current apartment about the same way as people tend to use a private room in the family home or at an institution; that is, as a place where one retires to do next to nothing. Maybe listen to music. Some of these people tend to use the communal rooms as the “main room” of the extended home, whereas others use both their own apartment and the group home more like “a drop-in base” when retiring from the real life which goes on elsewhere. Others, however, appear to really care for and put much effort into their private home.

The communal/staff rooms are described as more multifunctional than has been usual, at least in Norway. One such function that Jansson is pointing out is that of

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“defending” the privacy of the personal territory. This occurs because one is able to have most of the help and services needed by seeing staff in the communal rooms, and by this keep staff away from the private apartment. For some people staff rooms also appear to function as a bridge to the local community; appointments are negotiated and made; one drops by before going out, etc. But as mentioned above, the communal rooms also take on the shape of a home extension – the “real” sitting room.

The discussion of “weak ties” is foremost related to the contact with people in the residential area/ neighbourhood and the local community. Three different styles or attitudes are identified, and the “importance of weak ties” does foremost apply to a group she calls *informal contact seekers*. This is people operating much in the local community at public and semi-public places. They tend to have many acquaintances, and also have informal help to get around. Bus drivers would for example know their typical routes and help them get on the right bus and off at the right bus stop. Such a description does however not apply to all. Many residents operate less on their own and are less eager to use potential “weak ties”. Some prefer to go to organised leisure activities, typically activities organised for intellectually disabled people, whereas a last group tends to stay more at home having the social relations primarily with family and staff.

I mean that this dissertation brings important perspectives to the study of both homes of intellectually disabled people, and their social relations. It is well written and can definitely be recommended. I would however also like to raise a couple of critical points. The first is linked to the relations or interrelations between the different parts of the spatial structure, the apartment, the group home, the neighbourhood and the community at large. It is not always easy to see the relation between for example the architectural look of the area, the use of communal rooms, the attitude to one’s own apartment, and the social/community activity styles. One does clearly get the impression of interrelatedness, but how and how closely is sometimes a bit too vague.

I also wish to use this opportunity to discuss an issue that is not specifically aimed at this dissertation, but at a wide range of social research, including disability research. It is related to anonymousness. Subjects of research projects ought not to be recognised in publications, and in order to ensure this, social researchers also tend to obscure organisations, local communities, etc. In this respect Jansson’s publication is in keeping with the main stream of research in disciplines such as sociology and social work. This concealment, however, implies that she has to include lengthy descriptions of areas, architectural appearance, the way rooms look – and since such issues are so visual in nature, the reader will nevertheless have problems really grasping the points. I am convinced that drawings and pictures could have been used as an important analytical tool in her dissertation, and they would definitely be of great help to the reader. To publish such material is however habitually seen as a violation of research ethical regulations, but I can hardly see any significant harm being done with this approach. People who are familiar with the specific research area would recognise the group homes and some subjects anyhow, and others would not. The concealment also creates problems for

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replication and peer control of results. Jansson's dissertation, like some other social science work, would in my opinion have benefited from a less habitual application of the research ethical guidelines in question. Also, one should note that among other social sciences such as history, the "sociological concealment" would be regarded as next to unscientific.

This general critical remark should however not overshadow the main message of this review. Bibbi Jansson has presented an interesting and a recommendable study on the everyday life in and around group homes for people with intellectual disabilities.

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Reference:

Söder, M. (1993): Community Integration: On the importance of asking the right questions. In Sandvin, J. & Aa. Fasting (Eds.): *Intellectual Disability Research; Nordic Contributions*. NF-report 16/93, Nordlandsforskning, Bodø, pp. 1-27