

# STUDYING PERSONAL EXPERIENCES OF DISABILITY

- What happened to Verstehen when Einfühlung disappeared?

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*Abstract: For some time, disability researchers have shown a growing interest in personal experiences of disability. To some extent this interest can be understood as a response to the growing support for an emancipatory approach in disability research and the awareness that people with disabilities often have been deprived of their opportunities to speak for themselves. A striking characteristic of the studies of personal experiences is a lack of analysis and methodological discussions. It is argued that this, at least to some extent, can be understood as a strategy of the researchers not to fall back into reproducing oppressive, outsiders' perspectives. Furthermore, the absence of analysis seems to be the result of a 19th century paradigm of understanding based on the idea that the best way of understanding, for example, people with disabilities is through experiential closeness and cultural identification. However, according to current interpretative paradigms understanding demands a dialectics between experience-near and experience-distant descriptions. It is also argued that a true emancipatory approach in disability research demands the transcendence of personal experiences through in-depth analyses of the historical and socio-cultural conditions that influence the personal experiences of individuals with disabilities.*

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## **The interest in personal experiences**

The importance of first person, experiential perspectives have been emphasised by R. Bogdan & S. Taylor (1982). Their book, *Inside Out*, is one of the most comprehensive presentation of first-person accounts based on interviews with persons who are labelled intellectually disabled. Among

the pioneers in the field, R. Edgerton and L. Langness could also be mentioned. In a more anthropological tradition, they have studied everyday life perspectives of people with intellectual disabilities (Edgerton 1967, 1984, 1986, 1991; Langness 1986).

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one illustration of the growing interest in personal experiences of people with disabilities. In an overview, 15 years ago, Richards (1984) could not identify more than five British studies carried out during the previous 20 years, where people with intellectual disabilities participated as informants. According to Booth (1996) the number of recent studies of this type is much higher (see, for example Booth & Fielden 1992; Booth et al. 1990; Potts & Fido 1990; Flynn 1989; Cattermole et al. 1987; Sugg 1987; Lowe et al. 1986).

A more recent example of the celebration of personal experiences in disability research is the development of the so-called affirmative model by J. Swain and S. French (2000), two rather well known persons in British Disability Studies. They present what they consider to be a new model of understanding disability based on positive experiences of people being disabled:

In this paper we argue that a new model of disability is emerging within the literature by disabled people and within disability culture, expressed most clearly by the Disability Arts Movement. For the purpose of discussion we call it the affirmative model. It is essentially a non-tragic view of disability and impairment which encompasses positive social identities, both individual and collective, for disabled people grounded in the benefits of lifestyle and life

experience of being impaired and disabled. This view has arisen in direct opposition to the dominant personal tragedy model of disability and impairment, and builds on the liberatory imperative of the social model (Swain & French 2000, p.569).

First, the interest in personal experiences of disability is illustrated in the writers' claim that research should be based on personal experiences of disabled people and that such experiences have a special validity in illuminating meanings of disability that tend to be forgotten by non-disabled researchers. A Malaysian woman with a visual impairment, who was interviewed by the authors, for instance, presented an unusually positive way of understanding her disability in telling about how it had separated her from a poor and neglectful family and sent her to a good school at the age of five. She stated:

I got a better education than any of them (brothers and sisters) and much better health care too. We had regular inoculations and regular medical and dental checks (Swain & French 2000, p.574).

Experiences of being impaired, Swain and French argue, may also give people with disabilities a heightened understanding of the oppressions other people endure. French found, for instance, that visually impaired physiotherapists whom she interviewed could find advantages of being visually impaired in their work.

Secondly—and perhaps most important—the experiential perspective is expressed in the model of Swain and French by the priority attributed to experiences of disabled people in the analysis of how the disability should be understood. In fact, they argue that the emergence of the affirmative model depends on this priority of personal experiences over traditional, theoretical analyses. Personal experiences should be left to speak for themselves. Concluding, the authors admit that the affirmation model perhaps could play a role in the development of a theory of disability. However, they argue that theories are rarely explicit in the validation of experiences of disabled people but often explicit in invalidation of such experiences. Therefore experiences must be allowed to speak for themselves. “Quintessentially, the affirmative model is held by disabled people about disabled people. Its theoretical significance can also only be developed by disabled people who are ‘proud, angry and strong’ in resisting the tyranny of the personal tragedy model of disability and impairment” (Swain & French 2000, p.581).

### **The absence of analysis and methodological reflection**

Many of the studies presenting personal experiences of people with disabilities manifest a striking absence of analysis. To some extent, this can be understood as the researchers’ support to a program giving voice to a silenced group, and

the idea that it is necessary to give priority to a more experientially oriented research agenda. Another important reason seems to be that influential disability researchers, like Swain, French and Oliver (1996), more or less explicitly, question the legitimacy of disability research that is not directly based on personal experiences.

As disabled people have increasingly analysed their segregation, inequality and poverty in terms of discrimination and oppression, research has been seen as part of the problem rather than as part of the solution. Disabled people have come to see research as a violation of their experience, as irrelevant to their needs and as failing to improve their material circumstances and quality of life (Oliver 1996, p.140).

It is not surprising that this kind of critique has caused some concern among non-disabled disability researchers. In order not to fall back into the trap of reproducing oppressive outsiders’ perspectives they seem to avoid subjecting personal experiences to a theoretical analysis. Thus, the program of giving voice and the idea of oppressive research seem to have blocked the development of in-depth analyses of personal experiences of disabilities. Disability researchers, at least to some extent, have given up their special roles and responsibilities as researchers and replaced them by those of editors or political activists.

Here, one could perhaps object that researchers like, Oliver, have argued precisely that personal experiences of disability must be transcended by analyses in order to carry out an emancipatory agenda and that they thus have paved the way for theoretical analyses in disability research. However, the legitimacy of analyses in Oliver's case, and that of other similar researchers, to a large extent, seems to rely on the fact that they themselves have personal experience of disability. Even if it, of course, can be questioned how relevant and general these researchers' personal experience are with regard to studies of other people with disabilities, such experiences seem to contribute to a kind of legitimacy. Non-disabled researchers however, are in a different situation. For them it seems to have become very difficult to introduce an in-depth theoretical analysis without running the risk of being identified as oppressive.

### **Caught in a 19<sup>th</sup> century paradigm of understanding**

Another reason for the lack of analysis and methodological discussion in current studies of personal experiences of disability could be that advocates for the programme of giving voice to people with disabilities, and to some extent, also the British disability researchers mentioned above, seem to base their celebration of personal experience on the idea that experiential

closeness and identification constitute a golden way to a new and better understanding of disability. However, C. Geertz (1993), one of the most recognised interpretative anthropologists today, argues that the ideas of experiential closeness and cultural identification belongs to a 19<sup>th</sup> century paradigm of understanding that today has been replaced by a dialectics between what he calls "experience-near" and "experience-distant" perspectives.

An experience-near perspective is, roughly, one that someone—a subject, in our case an informant with a disability—might himself/herself naturally and effortlessly use to define what he or she sees and which he or she would readily understand when similarly applied by others. An experience-distant perspective is one that specialists of one sort or another—an analyst, a researcher, even a priest or an ideologist—employ to forward their scientific, philosophical or practical aims. "Love" is an experience-near concept, "object cathexis" is an experience-distant one (*ibid*, p. 57).

Clearly, Geertz adds:

The matter is one of degree, not polar opposition—"fear" is experience-nearer than "phobia" and "phobia" is experience-nearer than "egodys-syntonic" (*ibid*, p. 57).

Here, I will first discuss the 19<sup>th</sup> century paradigm as it earlier was used in

anthropology and C. Geertz's description of a development of the new interpretative paradigm especially elaborated in studies of different people with different experiences. Finally, I will present a Scandinavian example illustrating the new paradigm.

### What can we learn from anthropology?

Modern anthropology is characterised by a struggle against, what is often referred to as, "ethnocentrism", i.e. forcing one's own frames of reference on other people and thus running the risk of misunderstanding their ways of thinking and acting. In fact, Geertz (Ibid) argues that important steps in the development of anthropological methodology often have been taken in association with new insights into the dangers of trying to understand people from foreign cultures from an outsider's perspective. Studies of personal experiences of disability have interesting similarities to studies in anthropology. Here, ethnocentrism often is understood as a kind of "ablecentrism". Different terms have been used in the discussion of ethnocentrism: "inside" versus "outside", or "first person" versus "third person" descriptions, "phenomenological" versus "objectivist", or "cognitive" versus "behavioural" theories; or perhaps most commonly "emic" versus "etic" analysis, the last distinction referring to the understanding of a culture as it is understood by its own members. This distinction was originally borrowed from

the linguist, Kenth Pike (1954) who has coined the terms **phonetics** and **phonemics** in order to describe the difference between studying sounds of foreign languages from the point of departure of a universal theory (phonetics) or from the starting point of how sounds are actually used by the people who speaks a specific language (phonemics).

### "The natives' point of view"

In the history of anthropology, the first important disclosure of ethnocentrism concerned so-called "colonial anthropology". When Western researchers first started to describe other people, their cultures (Case 1927) and languages (Goodenough 1981), they generally commenced from the point of view of their own cultures and languages. Linguists who studied "exotic" languages used, for example, Latin grammar as a base to describe the foreign languages. E. B. Taylor's book *Primitive Cultures*, was based upon the idea that culture should be understood in terms of degrees of societal developments, from primitive to more advanced civilisations (cultures).

By simply placing nations at one end of the series and savage tribes at the other, arranging the rest of mankind between these limits [...] ethnographers are able to set up at least a rough scale of civilisation—a transition form the savages to our

own. (Taylor 1903, cited in Goodenough 1981, p. 48).

Boa's "cultural relativism" was an influential break away from this approach. He stated that all people have their own cultures. Therefore, we must study a culture as it is understood by its own members (see Case 1927). This idea constituted the first important critique of ethnocentrism and called for alternative methodological approaches that could do better justice to other peoples' special ways of thinking and acting.

Here, Bronislaw Malinowski also made a very important contribution. After having conducted extensive field-work, that enabled him to discover the special way of thinking of the people he studied—he presented a research strategy that has come to be regarded as the standard procedure in anthropology. He coined the credo that foreign cultures should be studied from "the natives' point of view"—an expression that is of course typical of his time but basically refers to the distinctions, described above, between insiders' and outsiders' perspectives.

### **The Malinowski scandal**

After Malinowski's death, his diary (Malinowski 1967) from the field studies was published. Clifford Geertz (1993) has described this as a scandal

and a new step in the history of anthropological method:

In much the same fashion as James Watson's *The Double Helix* exposed the way in which biophysics in fact gets done, Bronislaw Malinowski's *A Diary in the Strict Sense of the Term* rendered established accounts of how anthropologists work fairly well implausible. [...] The myth of the chameleon fieldworker, perfectly self-tuned to his exotic surroundings, a walking miracle of empathy, tact and patience and cosmopolitanism, was demolished by the man who had perhaps done most to create it (Geertz 1993, pp.55-56).

In his diary, Malinowski had rude things to say about the natives he had been living with, had spent a great deal of his time wishing he was elsewhere and projected an image of a man about as little complaisant as the world has seen.

Much of the debate among anthropologists concerned Malinowski's moral character or lack of it. However, the importance of the Malinowski scandal, according to Geertz (Ibid), was that it raised an important epistemological question concerning interpretation. In the context of anthropology, the following question can be posed:

If we are going to cling—as, in my opinion, we must—to the injunction to see things from the native's point

of view, where are we when we can no longer claim some unique form of psychological closeness, a sort of transcultural identification, with the subjects? What happens to *verstehen* when *emföhlung* disappears? (Ibid, p. 56).

### **From “Einföhlung” to the dialectics between experience-near and experience-distant descriptions**

Geertz’ answer to the epistemological question is, that the Malinowski scandal, and similar other experiences, have forever closed the road of the emphatic model in social science understanding other peoples’ lives. However, other interpretative models have paved the way for alternative paradigms and Geertz’ own work provides an example. In *Local Knowledge—Further Essays in Interpretative Anthropology* (1993), he presents an interpretative approach characterised by a dialectics between personal, experience-near perspectives, and more experience-distant, theoretical socio-cultural perspectives. People, whose personal experiences we want to study and understand, he argues, also belong to social communities, cultures or subcultures. When we listen to their voices, they tell us about these communities or cultures from their own point of view but they do not tell us the whole story about them. This was pointed out by Bogdan & Taylor (1982)

already in their classic autobiography of persons with intellectual disabilities:

The autobiography cannot and does not provide complete understanding of a subculture, it does provide an initial view of the world through the eyes of an insider." (Ibid, p.18).

The basic idea of Geertz’ interpretational dialectics is that an understanding of other peoples’ experiences and lives only is possible if we complete the experience-near perspectives of the informants by theoretical, experience-distant analyses. Thus, an interpretative analysis may well be founded on the informants’ experiences but it must also include other kinds of data, the relevance of which it is often hard to see from an insider’s perspective and the analysis therefore also must be guided by experience-distant perspectives.

### **A Scandinavian example**

An illustration of the dialectic interpretative approach can be found in a recent Scandinavian study of what it has been like for people with intellectual disabilities to grow up in Sweden during the golden age of the policy of integration (Gustavsson 1998). The everyday lives of ten young men and women were studied for several years. The first step of the study can be characterised as an experience-near approach. This means that data were collected by interviews and

participant observation and that the preliminary understanding of these data stayed very close to the participants' own perspectives.

One interesting pattern in the participants' experiences was that they expressed a striking faith in their own abilities and rights to live ordinary lives, in the sense of being able to get a driver's license, managing a life in an apartment of their own, managing a job or being able to bring up a child. Such self-assured attitudes have often been understood from a psychological perspective, questioning the realism in the faith expressed by the informants with intellectual disabilities. First, the intellectual disability seems to have raised the suspicion that persons with such disabilities, who express faith in their abilities, simply do not understand the importance of their own shortcomings. Furthermore, the personal expressions of self-assurance also often are interpreted as psychological denial, indicating that the persons in question rather experience a threat against, than a faith in, their own abilities and rights. The most well known expression of this interpretation is probably R. Edgerton's (1967) book, *The cloak of competence*. Here, he argues that persons with intellectual disabilities, encountering the norms and expectations of a non-disabled society, tend to deny their disabilities and shortcomings in order to avoid being stigmatised. Thus, the personal experiences expressed by the persons studied by Edgerton are turned

almost upside down in the interpretative analysis.

Findings in the Scandinavian study seem to provide a point of departure for an alternative understanding. Important findings in this study were difficult to make sense of within the context of a psychological interpretation. Few informants did, for instance, try to hide their shortcomings. On the contrary, many of them often explicitly reminded other people of their disabilities, for example when they wanted to stress their own rights to special services or support. Furthermore, striking similarities in the individual informants' ways of thinking and expressing themselves indicated that their self-assured attitudes could be understood as a manifestation of a socially shared perspective that was based on special experiences not usually known by non-disabled people. In fact, the informants' faith in their own abilities and rights could best be understood as expressions of socially anchored perspective on disability and what it means to live with a disability. The fact that these experiences were supported by several persons contributed in an important way to the taken for grantedness of the abilities and rights. All this pointed to a new way of understanding the informants in the Scandinavian study.

However, in order to discover and validate this alternative understanding it was necessary to transcend the informants' own experiences and to

introduce a socio-cultural, theoretical framework. The crucial meaning of the similarities between different persons' experiences and perspectives was only possible to discover from an outsider's perspective. And the illumination of the meaning of such shared perspectives demanded references to existing socio-cultural theories. The socio-cultural framework that here turned out to be most productive was a theory of the social organisation of meaning described by the Swedish social anthropologist U. Hannerz (1992). He is particularly interested in how subcultures or micro-cultures are born, but an important point in his theory of social meaning-making is to bring the analysis all the way down to the most elementary unit of meaning-making, where only two, three or four people are involved. This made it possible to use his theoretical framework as a point of departure also in understanding the shared perspectives and meaning-making that was observed among the participants in the mentioned study.

Hannertz' idea—and here he points to inspiration from Hughes (1961)—is that social meaning-making is founded on shared experiences articulated in shared perspectives. A given reality, such as some people's shortcomings in the sense we usually call disability, is experienced and understood differently by individuals with and without personal experience of disability. Furthermore—and most important—individuals who share a special perspective and have the

opportunity of communicating their special experiences with one another, are able to develop a socially anchored, shared perspective that they experience as much more real and self-evident than their individual views. Hughes has pointed to some important factors to consider in such elementary meaning-making:

Whenever some group of people have a bit of common life with a modicum of isolation from other people, a common corner in society, common problems and perhaps a couple of common enemies, there culture grows (Hughes 1961, p.28).

This seemed to be precisely the case of the participants in the Scandinavian study. The informants who expressed faith, for instance, in their ability to bring up a child of their own were actually surrounded by a network of significant people who shared their views. There was also some evidence that the informants turned to this network for support whenever other people looked down upon or excluded them. Thus, the observed everyday strength of the informants' faith in their own abilities and rights could very well be understood as the result of shared experiences and perspectives

It is true, that these shared perspectives, to some extent, were maintained in opposition to views held by non-disabled people, who often, for instance, thought that intellectual

disability was impossible to combine with parenthood. However, from the socio-cultural theoretical perspective the most natural way of understanding this opposition was not as a psychological denial but rather as an alternative social perspective maintained by persons who felt misunderstood by other people lacking real experience of disability.

All the important social dimensions of the alternative perspectives were not possible to identify from an individual's experiential perspective. The discovery of the alternative perspective demanded an overview of how different individual perspectives could constitute a shared perspective on a higher social level. And this was only possible to do in the second, experience-distant phase of the interpretative analysis. Of course, some informants also had a lived experience of the mutual understanding that they acted on in their everyday lives, as lived experience, but from their individual points of view it was not possible to reach a satisfactory understanding of the socially shared perspectives.

Another productive consequence of the experience-distant approach was that it pointed to the importance of a social-historical contextualisation of the informants' experiences. In fact, there also turned out to be interesting similarities between the participants' shared faith in their own abilities and rights and the official disability policy of the time when they had grown up. When the informants argued, for

instance, that they could manage a certain task, they often took for granted that they also had the right to a certain assistance as a consequence of their disability. Similar ways of reasoning are easy to identify in the Scandinavian disability policy of the last 20-30 years and it would not be surprising if these official ideas have been mediated to the informants by parents and professionals thus influencing and supporting the discovered perspective. In fact, this influence could have been an important circumstance in the construction of the alternative perspectives.

The insights gained through the experience-distant, socio-cultural analysis was subsequently brought back and checked against the personal experiences in a third step of the dialectical analysis between experience-near and experience-distant approaches. As indicated above, the discovered perspectives and their social meanings were very difficult to identify from an insider's perspective, i.e. to confirm in spontaneous statements from the participants. However, a few of the participants, when presented with the descriptions of the shared perspective and its supportive function, later could confirm that they experienced a kind of "home-world" that had been very important for them in their struggle to maintain a faith in their own abilities and rights. Furthermore, the existence of the shared perspectives could be confirmed indirectly by the observations of how they often sought support from others, sharing the same perspective, in

situations where they felt excluded or depreciated.

Thus, the dialectics between experience-near and experience-distant interpretative analyses was important in the identification and validation of the socio-cultural understanding of the special perspective described above. From an emancipatory point of view, it is not difficult to see the value of identifying such an alternative, shared perspective on disability and what it means to live with a disability. Being seen and understood as an individual driven by psychological defences and a lacking sense of reality can easily contribute to a reduced self-esteem and learned helplessness. On the contrary, the recognition of a true experiential foundation for alternative perspectives is likely to facilitate the empowerment of people who earlier have been understood as incompetent or deficient. Experiences from the empowerment of other minorities and stigmatised groups in our society indicate that deconstruction of existing incapacitating understandings of the members of such groups can contribute to a growing collective consciousness of rights and new opportunities for the members of such groups. Of course it is true that the emancipatory power of this kind of research, to some extent, depends on the fact that people with intellectual disabilities have access to the results. However, another—and perhaps more important—way to empowerment in the case of people with intellectual

disabilities might be that the new knowledge influences professionals in the disability services making them aware of the incapacitating nature of traditional psychological ways of understanding disability and of the emergence of new alternative perspectives based on the lived experiences of disability. As these alternative perspectives were difficult or impossible to discover from the horizons of the individual informants, the emancipatory power of the discovery demanded the transcendence of personal experiences of disability by experience-distant, socio-cultural and historical analyses. This emphasises the importance of methodological awareness in carrying out the emancipatory agenda in disability research.

#### References:

- Bogdan, R.B. & Taylor, S. (1982) *Inside out. Two first-person accounts of what it means to be labelled "Mentally Retarded"*. Toronto: University of Toronto Press.
- Booth, T. (1996) Sounds of still voices: Issues in the use of narrative methods with people who have learning difficulties. Published in (ed.) L. Barton *Disability & Society: Emerging issues and Insights*, pp. 237-255. Harlow: Addison Wesley Longman Ltd.
- Booth, T. & Fielden, S. (1992) *Second opinions: Students' views of Swallow Street Centre*. Unpublished report, Department of Sociological Studies, University of Sheffield.
- Booth, T., Simons, K. and Booth, K. (1990) *Outward bound: Relocation and Community Care for people with Learning Difficulties*. Buckingham: Open University Press.
- Case, C. (1927) A crisis in Anthropological Research. *Sociology and Social Research*, 12(1), pp.26-34.

- Cattermole, M., Jahoda, A. and Markova, I. (1987) *Leaving Home: The Experience of People with a Mental Handicap*, Department of Psychology, University of Stirling.
- Edgerton, R. B. (1967) *The cloak of competence*. Berkeley: University of California Press.
- Edgerton, R.B. (1984) The Participant-Observers Approach to Research in Mental Retardation. *American Journal of Mental Deficiency*, vol. 88, no.5, pp. 498-505.
- Edgerton, R. B. (1986) A Case of De-labelling: Some Practical and Theoretical Implications. In Langness, L.L. & Levine, H. G. (eds.) *Culture and Retardation. Life Histories of Mildly Mentally Retarded Persons in American Society*. Dordrecht: D. Reider Publishing Company. pp. 101-126.
- Edgerton, R. & Gaston, M.A. (1991) *I've seen it all!* Baltimore: Paul H. Brookes.
- Flynn, M. (1989) *Independent Living for Adults with Mental Handicap*. London: Cassel.
- Geertz, C. (1973) *Interpretation of Cultures*. New York: Basic Books Inc.
- Geertz, C. (1993 ) *Local knowledge*. London: Fontana Press.
- Goodenough, W. H. (1981) *Culture, language and Society*. Menlo Park: The Benjamin Cummings Publishing Company, Inc.
- Gustavsson, A. (1998). *Inifrån utanförskapet (An insider's perspective on being an outsider)* Stockholm: Johansson & Skyttmo förlag.
- Hannerz, U. (1992) *Cultural Complexity. Studies in the social organization of meaning*. New York: Columbia University Press.
- Hughes, E. (1961) *Student Culture and Perspectives*. Lawrence: University of Kansas Law Press.
- Lowe, K, de Paiva, S. and Humphreys, S (1986) *Long term Evaluations of Services for people with a Mental Handicap in Cardiff: Clients' Views*, Mental Handicap in Wales - Applied Research Unit.
- Malinowski, B. (1989) *A Diary in the Strict Sense of the Term*. Stanford: Stanford University Press.
- More, M., Beazley, S. & Maelzer, J. (1998) *Researching Disability Issues*. Buckingham: Open University Press.
- Oliver, M. (1996) *Understanding disability. From Theory to Practice*. The politics of disablement. Critical Texts in Social Work and the Welfare State. London: The Macmillan Press Ltd.
- Pike, K. (1954/1967) *Language in Relation to a Unified Theory of the Structure of Human Behavior*, Part 1. Summer Institute of Linguistics. (2nd. rev. Ed.) The Hague: Mouton.
- Potts, M. & Fido, R. (1990) *They Take My Character*. Plymouth: Northcote House.
- Richards, S. (1984) *Community Care for the Mentally handicapped: Consumer perspectives*, University of Birmingham.
- Sugg, B. (1987) Community Care: the consumer's point of view', *Community Care*, 645(22) January. p. 6.
- Swain, J & French, S. (2000) The Affirmation Model. *Disability & Society*. vol.15, no.4, pp.569-583.

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