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> Loosening Bonds and Changing Identities: Growing Up with Impairments in Post-War Norway

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Abstract

This article reports on an in-depth interview investigation concerning the life histories of 70 people with various impairments, representing three different generations or age groups. The central aim of the study is to investigate how social change and the evolution of the welfare state influenced life conditions and opportunities for disabled people in Norway during the second half of the twentieth century. Methodologically, the study also suggests that biographical research offers the means to make links between the lived experiences of disabled people and the wider context of social and institutional change in disabling societies. The aims of this article are to present some of the main patterns detected from the overarching analysis, and thereby to demonstrate some of the implications of a biographical approach for disability studies.

Introduction

As Engelstad and Kalleberg (1999) rightly point out, sociology and the social sciences in general are inevitably historical disciplines. The inevitability, they argue, follows from the simple fact that both the social sciences and the society they study are historical phenomena. It could be added that social sciences, and sociology in particular, are about people's lives, and people's lives are always located in social and historical processes. Or, as C. Wright Mills put it; 'Social science deals with the problems of biography, of history, and of their intersections within social structures' (Mills 1952, p143). People's lives can only be understood in relation to the context in which they take place.

The research tradition that most explicitly takes the historical dimension of individual lives into account is what, to use a generic term, has been named the biographical tradition, or life-history methodology (Schwandt 1997). Over the past two decades, biographical approaches have become increasingly attractive to social scientists, a trend that must be understood within the historical context of social science itself. The shift in parts of social theory, from post-war positivism and social determinism to pure subjectivism and social constructivism, has created a new interest in people's lived realities, and in the interplay between individual experience and action, and social and cultural change.

Studies of individual life courses, or the unfolding of individual life experiences over time, often focus on specific phases, reflecting how life courses are to a large extent culturally structured. Although the shape, predictability, and duration of different life courses or trajectories vary considerably, both individual and cultural expectancies suggest certain courses of events and certain regularities in the sequencing of transitions and life experiences within a given cultural and historical context. Such expectancies and regularities may function as cultural norms, to which other paths and directions are compared and judged. Irregular sequencing of events may thus be seen as abnormal and certain changing events perceived and experienced as disruptions (Becker 2000).

Impairment is very likely to influence a person's biography, not only because it challenges cultural images and expectancies, but because it directly affects access to important resources. People with impairments are disabled in a society shaped and structured by and for culturally prescribed patterns of life. As Priestley (2001) points out, disability is about differential access to economic, social and cultural capital, and therefore also about the distribution of life opportunities. But the shape and outcome of such differential distribution, as well as other possible influences, are likely to change over time, which makes it interesting to study individual life courses not only over the entire life span, but also across generations.

This article reports on a large study based on qualitative life-history interviews with seventy people with impairments, belonging to three different cohorts or generations. The aim of the study was to analyze and compare the life experiences of people growing up and living with impairments in different phases of post-war Norway. An important question was to ask how the gradual evolvement of the welfare state and the development of disability organizations influenced the opportunities, identity and courses of life of people with impairments. The article presents some of the main patterns detected from the study and discuses some possible advantages of a biographical approach to disability studies.

The biographical tradition in social science

The recent publication of *The Turn to Biographical Methods in Social Science* (Chamberlyne et al. 2000) reflects a long growing interest in biographical research in European social science. The purpose of the book was not only to disseminate examples of contemporary biographical research in Europe, and the course of style and methods it has taken in different countries, but also to describe the forces behind this methodological turn.

It is argued that this turn reflects a growing recognition that social science has become too detached from people's lived experiences. Thus, the turn to biographical methods is also partially a return to classical perspectives and methods in social science, such as historicism (or anti-naturalism), intentionalism and interpretivism (Fay 1996, Giddens 1993, Schwandt 2001), and more specifically to the biographical tradition developed within what has been known as the Chicago school of sociology. The most important reference to the biographical work done at the University of Chicago is Thomas and Znaniecki's extensive (18 volumes) study The Polish Peasants in Europe and America, published between 1918 and 1920. This was a path-breaking study of the forming of personal and cultural identity among Polish immigrants, based on their correspondence with countrymen back in Poland. Besides its methodological significance, the most important contribution from this study was the division made between the individual and the social or between objective factors and subjective exposition (Plummer 1983).

Biographical analyses are often characterized by detailed inquiry into the dynamic interplay between historical and structural conditions, on the one hand, and people's individual considerations, choices and actions on the other. Biographical research covers a number of research traditions, based on biographical materials, such as letters, diaries, autobiographies, and biographical interviews (life stories). It also covers a number of different approaches or types of analyses.

One such approach is based on studies of generations. Peoples' lives are situated in history, and the fundamental anchorage in history is the time of birth. Generation refers to an aggregate of people born around the same time, similarly positioned, in terms of age, in relation to the social and historical processes taking place in the society where they live. A prominent reference to this generation perspective in sociology is Karl Mannheim's 1928 essay The Problem of Generations. Mannheim held that:

The fact of belonging to the same class, and that of belonging to the same generation or age group, have this in common, that both endow the individuals sharing in them with a common location in the social and historical process, and thereby limit them to a specific range of

potential experience, predisposing them for a certain mode of thought and experience, and a characteristic type of historically relevant action (Mannheim 1952, p291).

The young and the old see things differently, not merely because of their different age, but because they have different experiences and different interests. Older people have experiences from long before the presently young were born, and so the historical incidents that occur in their common lifetime are experienced in quite different phases of life. A generational study allows comparison of biographies that are differently situated in time, and analyzes collective perceptions and patterns reflected both within and across generations.

About the study

The study reported on here is a generational study based on life-history interviews with 26 people, with different impairments (visual, hearing and mobility impairments), representing three generations or age groups. When the interviews were conducted, in 1998 and 1999, one third of the interviewees were in their early sixties, one third in their early forties, while the youngest were in their early twenties. The interviewees came from all over Norway, and represented a broad spectrum of communities and social and educational backgrounds. All the interviewees contacted us, after receiving an invitation through an association of which they were a member, or having seen a magazine advertisement. The interviewees were fairly equally distributed across generations and types of impairment. Twenty had a hearing impairment, 21 had a visual impairment and 25 had mobility impairment. Twenty-five were from the youngest generation, eighteen from the middle generation and twenty-three from the oldest generation. Thirty-nine of the interviewees were women.

The interviews lasted a minimum of one and a half hours, and most ran for well over two hours. Most of the interviews were conducted in people's homes, some at their work place, and some at a cafe or restaurant. The interviews with Deaf informants were conducted in sign language. Each person was given additional information about the study at the outset and informed that they could withdraw consent or stop the interview at any time. They were also informed that what they said would not be presented in a way that could identify them.

To perform a qualitative study with seventy long interviews is rare and not necessarily advisable. However, the study was in itself an attempt to try out new ways of handling a large qualitative data set. The interviews were not transcribed, but coded and analyzed on tape (digitized on disc), using a data program called KIT. Our experience is that it is possible, and for some purposes even desirable, to include such a large data set in one study, but that it requires technical support to help the researcher maintain an overview, to allow for categorization, display and retracing

of the different segments of data. It was not possible to do a very detailed and rigorous analysis of the entire material, but the way the data was organized allowed for a deeper analyses and comparison of selected segments (Sandvin 2000).

Three disability generations

The interviewees have grown up and had their 'phases of orientation' (Manheim 1952) in different historical periods. Those representing the oldest generation were born in the 1930s, were children during the war, and entered adulthood in the very early phase of the welfare state. The middle generation were born in the 1950s, grew up in a period characterized by social and economic safety, but with a growing distance between generations. Different from the oldest generation, they experienced a separate youth culture. The youngest generation were born in the 1970s, and made their most decisive choices in a 'market' where the number of choices according to education and life styles exceeded all previous generations.

With respect to growing up with impairments, there are also distinctive differences between the three generations. Our oldest interviewees grew up in a time characterized by organization building, and the fight for basic collective rights. The interviewees from the middle generation grew up with the expansion of the welfare state, and were still fairly young at its height. Ideologically, the rhetoric had changed from collective rights to normalization and integration but the first campaigns against segregation came too late to have any real impact on their own schooling. Our youngest interviewees, who are still fairly young, have grown up in a time of relative prosperity, and surrounded by ideological concepts like freedom of choice, autonomy and self-determination.

People with impairments are disabled by society in numerous ways. In Mannheim's (1952) conceptual framework 'those groups within the same actual generation which work up the material of their common existence in different specific ways constitute separate generation units' (p291). People with impairments can be said to constitute such a 'generation unit' in the sense that they share some fundamental experiences of disability. While this is true, across generations, the shape and outcome of these experiences, and the meanings attached to them are likely to change over time. This gives grounds for a generational cohort study limited to people with impairments. Considering the size of the data set, the space available here allows for only a very general picture of the patterns and differences revealed from the study. However, it is a hope that it may facilitate a discussion about the suitability and value of a biographical approach to disability studies.

The oldest generation

The most characteristic feature from our interviews with

representatives from the oldest generation, although somewhat less obvious among interviewees with mobility impairments, are similarities of trajectory. With very few exceptions, all the interviewees from the oldest generation went to special schools, run by organizations for disabled people. Some of the visually impaired interviewees even went to an orphanage from the age of three to six. From compulsory school, almost everyone went on to segregated vocational education, at schools run by the same organizations. After vocational education, where the options were limited to a standardized set of occupations regarded suitable for people with their kind of impairment, most were preoccupied with the struggle for work.

The struggle for work was probably the most frequently cited and important element of the narratives told by people representing the oldest generation. This was before social security was introduced on a national level in Norway, and there were few alternatives for economic support outside the labor market and the family (individual municipalities had introduced social security schemes from before 1920, primarily old age pensions but also some disability pensions, (see Hanssen et al. 2001)).

Biographical studies with non-disabled participants from similar cohorts have found distinct gender differences reflected in narratives of work (Almss et al. 1995), but such differences are not clear among our interviewees and work was equally important to women and men in this generation. One woman explained it like this:

You know, for a woman at that time, it was important to be a good match, and if you were a good match, you were provided for. But I knew I wasn't a good match, so I had to get an education, in order to get a job.

Another woman expressed some of the gravity related to the question of work:

I didn't want to go back to Huseby (the segregated center for vocational education), but the thought of not getting a job, scared me to death.

Despite education, few managed to find work on the open market and many worked for shorter or longer periods for their respective associations, some for all or most of their working years. Many experienced harsh times, especially in the early years, and some took early retirement when that, eventually, became an option. But their narratives reflect a strong desire for work, not only because of necessity or the salary, but also because of the satisfaction it gave those with an ordinary job, and correspondingly the dissatisfaction for those without. One of the interviewees, also a woman, said of her experiences in an ordinary work place: 'To be respected for who you are, and for what you do, that's the most important'.

The last point I will make in this short presentation of the oldest generation is the strong sense of association with a collective of people sharing the same kind of impairment. With one or two exceptions, all of our interviewees from this generation were active members of their respective organization, be it the associations for Deaf or hard of hearing people, the association for blind people, or the union for people with physically impairments. The associations represented the social and cultural anchorage for our interviewees from the oldest generation. They still express a strong collective identity, and regret that the solidarity and social bonds they experienced in earlier days are about to weaken.

But what we must bear in mind is that these associations, and the possibilities for education, protection and support that they represented, were crucial for this generation of disabled people, almost as important - and for Deaf people probably more important - than their own families. People from the same generation often knew each other personally, because they had been to the same school, the same courses or summer camps, met at sporting events, gained their further education at the same place, etc. There were simply no alternatives. Since the general life paths of society were closed to most people with impairments, special paths became proportionately more important.

Norway is a small country, and in the early days of segregation, people with visual and hearing impairments had only one special school each, and one vocational institute. The lives of people with impairments from this generation were, to a large extent, arranged and formatted by their respective organizations. People's relationship to these associations was more like kinship than membership, and this explains many of the similarities in their life course trajectories.

The middle generation

The interviewees representing the middle generation in our study also expressed a strong collective association. Many of them have had, and still have, central positions in their respective organizations. This engagement, however, does not spring from necessity, or from a kind of naturally developed kinship, but is instead much more consciously chosen.

It is important to mention here that the narratives told by the interviewees with mobility impairments were more heterogeneous than those told by people with sensory impairments, and most distinctly so in the middle generation. There are probably two main reasons for this. First of all, the interviewees with mobility impairments constitute a much more heterogeneous group in terms of impairment. Secondly, the Norwegian Association of the Disabled, where most of our interviewees with mobility impairments were members, was the most progressive of our disability organizations at the time.

Almost all of the interviewees with mobility impairments

from the middle generation went to ordinary school, while most of the interviewees with sensory impairments had gone to, and continued to defend, special school. All of the Deaf interviewees, with sign language as their first language, argued for the necessity of schools for deaf children. Blind people also defended special schools because they feared that ordinary schools would not be able to provide blind children with the necessary competencies to cope in a seeing world.

However, the interviewees from the middle generation were not bound to the associations in the same way as the oldest generation. It was now the national state that ran the special schools, even though the organizations still played an active role. The representatives from the middle generation were organizationally active in a way more similar to those active in political or religious organizations. Their engagement had a more practical and political motivation. The associations gave them access to a range of services, courses and leisure activities and offered a united voice to the authorities.

This is not to say that their engagement did not have cultural and self-defining elements. For Deaf interviewees the association represented a very important cultural community, a community of communication, with sign language as the constituting and uniting element. But the other associations also played important cultural and self-defining roles. The association of blind people administers important cultural resources, such as the Braille library, the production of Braille literature, education in Braille, etc. But the importance of self-identity differs in character from the oldest generation, first in the degree of consciousness and reflection. The conscious association with an organized collective was a deliberate choice, with a ceremonial character for some: one of our blind interviewees, a woman, describes entering the blind union in a way reminiscent of a religious conversion, beginning with personal crisis, followed by 'awakening', reinterpretation of self, becoming a member, and finally a committed engagement to the goals and tasks of the organization. She talks about 'coming through'.

Education and work also played an important part in the narratives of the middle generation. But here too, the orientation differs distinctively from that of the oldest generation. In place of the necessity of income and strategic choice of education (within set limits), the middle generation talk much more about their own personal interests, and refer more to this than necessities or practicalities in explaining their motivation and choices of education and occupation. Even more characteristically, they use much of the time to talk about and criticize the lack of access to educational programs, the insufficiency of economic support schemes, the inaccessibility of public transport, public buildings, and of large parts of the labor market.

One could say that those of the middle generation are children of the welfare state and, in many respects, as dependent upon it as the oldest generation was upon the organizations. Certainly, the oldest generation was more

trapped, in a strictly defined life path. The middle generation had the economic base for a much wider orientation, but even this was relatively strictly regulated by the state. Perhaps even more importantly, the orientation of the middle generation was also limited by expectations inherited from the special schools and from a longstanding identification with the disabled collective.

The youngest generation

The youngest generation differs substantially, in many respects, from the two older generations. First of all, while the oldest generation, and to some extent the middle generation, can be described as segregated generations, the youngest generation barely relate to this concept. All but a few, of the Deaf interviewees, from this generation have attended ordinary schools. This shift is most significant among the interviewees with visual impairments. Special school was still the default path for visually impaired children when the middle generation attended school and, as we have seen, our visually impaired interviewees from the middle generation also defended special schools. None of our visually impaired interviewees from the youngest generation went to special school, and for them the very idea was absurd. When we asked why, one of them said: 'Look at them! (those who went to special school). They are all strange, and that's because of the special school. I don't want to be strange'.

This is only one expression of a general characterizing feature of the youngest generation. They do not want to stand out, to be different, and they do not see themselves as very different from other youngsters. What the two older generations saw as opportunities - 'despite' being disabled are now taken for granted by the youngest generation. Perhaps more interestingly, hardly any of the interviewees from the youngest generation used the concept 'us', referring to people with the same impairment as themselves. Not even among young Deaf people. Very few expressed any strong relation to the traditional collectives at all. Instead they talked about friends and classmates without making any distinction between people with and without impairments. One partial exception is that the Deaf interviewees talked much about the importance of access to a sign language community, but even they talked about the freedom of choice. 'We need both', they said, 'The Deaf community is simply too boring. I think it's partly a class thing. We have better education, and the older in the Deaf community don't understand us'.

While the oldest generation was characterized by similarities of trajectory, the middle generation showed a greater variation, depending on when the impairment appeared, and on differences in social and cultural capital. Interviewees from the youngest generation, however, seem to develop a more personal life project, with no reference but to their own self-identity and interests. They have chosen very different lifestyles, with the same variation regarding social

and sexual orientation that would be found amongst their generational peers. Thus, they are as different as anybody else. The heterogeneity that characterized those with mobility impairments from the middle generation is equally apparent among those with sensory impairments from the youngest generation.

This is not to say that all social arenas now are accessible to people with impairments, and that we have reached a level of full participation and equal opportunity. On the contrary, there is at least one important issue concealed by the picture drawn above. While the youngest generation orient themselves - as a matter of course - in the same direction as their non-disabled friends, they are not equally likely to succeed. The interviews from the youngest generation reflect a greater vulnerability than do the interviews from the two older generations, and probably more than would be found among the majority of youngsters from their own generation. Loneliness, a feeling of insecurity, and even stories of exploitation and abuse, were not uncommon. And this common experience requires much more from a disabled person in order to succeed, compared to a non-disabled person, be it to gain an education or to find friends. As one of the interviewees said, 'when you are disabled, you must be perfect to be accepted. I didn't use hours in front of the mirror before I went out with my mates, and I didn't read all the cool magazines. So, I guess, it's my own fault'.

This feeling of having none to blame, but themselves, is characteristic for many of the young interviewees, and perhaps something that makes them more vulnerable than the older generations. The middle generation in particular knew very well whom to blame. The two older generations also had better support, even supervision, from a collective disability community, that the youngest generation does not. But reversing this development does not seem as a realistic option, and certainly not desirable as seen from the young interviewees' point of view. Freedom of choice and the personal responsibility to form their own destiny and self-identity is not only something these youngsters have captured or chosen, but also something they are fated to. And young people, independently of personal advantages, seem to have accepted that as a fact. This represents a double vulnerability, because it adversely affects the inclination to join or form collectives and political alliances.

The acceptance of personal responsibility for self-identity does not mean that our young interviewees are unaware of the systematic discrimination they are exposed to. They are very aware of it and they do not accept it. Several of them have taken part in demonstrations, written to newspapers and occasionally taken part in political hearings, yet none of them are what we would call politically active. The barriers they fight are first and foremost the ones that obstruct their own individual endeavors. Very few see any point in joining the existing associations, which are 'more about socializing, whimpering and service, than about working

for the interests of disabled people', as one of the young visually impaired women expressed it. And she continued:

I wish there were more of a fighting spirit (in the organizations), which really could confront politicians with the reality. The associations we have, and the ways in which they present disabled people - it is not how I am, and it is not how I want to be presented.

So, instead, they take responsibility to present themselves. The moral right to participate is something taken for granted, and so is the fight to be able to enjoy these rights. The barriers that the oldest generation took as a fact, and the middle generation took into account and challenged collectively, are met by the youngest generation with outrage and dejection, sometimes with a certain incomprehension; 'Are we still there? How stupid can people be? Hasn't he seen a wheelchair before?'. But in the end they have no-one they can really trust, or blame, but themselves.

Patterns of change

The picture drawn above reveals some of the most distinctive patterns of change from the oldest to the youngest generation reflected in our overarching analysis. One such pattern is related to what we might call forms of differentiation. The early post-war period was characterized by clear distinctions between normal and abnormal, functional and dysfunctional, order and disorder, and the modernistic vision of doing away with all sorts of disorder. The social organization and differentiation of the period was based on such distinctions becoming collectively shared representations of reality. It reflected what Foucault (1974) calls the practice of ordering. While the oldest generation did little to oppose these culturally defined categories, they were challenged by the middle generation and hardly understood by the youngest generation. The youngest generation reflects a much more individual differentiation, or a differentiation that mirrors more or less the same variation of interests, preferences and lifestyles that are likely to be found in the rest of the young population.

Another feature of change, strongly related to the first, concerns the association with formal and informal collectives. The oldest generation reflects a strong association to such collectives, and it is clear that this relation was already important in their early 'phase of orientation' (Mannheim 1952). This was also the case for the middle generation, although in a less compelling and more optional or reflexive way. By contrast, the youngest generation reflects a rather indifferent, and sometimes even rejecting attitude towards the traditional collectives.

This relates to some distinctive changes regarding selfidentity from the oldest to the youngest generation. The similarities in values, perceptions and attitudes amongst the oldest generation give the distinct impression of a collectively shared identity (or identities), difficult to distinguish among those from the youngest generation. That is not to say that our youngest informants have a less conscious or reflexive relationship to their disability status than do the older generations - far from it. But our youngest interviewees were not segregated from their early school years, as were the two older generations. Instead, they were exposed to more or less the same influences as other youngsters. Self-identity has, over recent decades, become a much more open and subjective undertaking (Berger 1973, Giddens 1991), and the consequences of disability on self-identity are more individually negotiated, in the context of other values and influences. This shift constitutes, as we have seen, both opportunities and risks, and suggests new conditions for political action.

What does biographical research have to offer disability studies?

The story just told provides a rather superficial picture of the lived experiences revealed from this study, and of changes in the possibilities for Norwegian disabled people to make their own way in the world. What I have tried to show, although perhaps more implicit than explicit, is that relating peoples' accounts of lived experiences to features of social history, offers a fruitful route to understanding the structuration of life opportunities and social differentiation.

Research that claims to say something about people's lived experiences must in some way or another build on personal accounts of such experiences. Much social research produced around disability fails to meet this requirement. But to base research on personal accounts of disabled people is not sufficient to understand the social processes of disability itself. As Wengraf (2000, p140) argues, 'in order to understand the voice of the Other as fully as possible, we must explicitly go beyond simple recycling of the verbatim text, and even beyond sophisticated formal text-analysis'. What lies beyond is first of all the relating of verbal accounts to context, and the widest possible version of context (Scheff 1997).

Biographical methodology offers disability studies ways to make links between the lived experiences of disability and the macro-social context in which disabled lives are played out (Priestley 2001). Introducing generation allows an analysis of the influences at play in the lives of disabled people living through the same historical period. Thus, biographical studies of successive generational cohorts offer ways to analyze how the interplay between individual lives and macro-social contexts are influenced in periods of social change. This is valuable for several reasons. First, it helps us to understand and demonstrate the social constitution of disability. The fact that both the experiences and

consequences of disability change from one generation to another is a solid defense against essentialism. Secondly, it allows for a more detailed analysis of the disabling processes of society. Studies that locate patterns of lived experience in historically situated social institutions, or compare the entering of certain life phases under different historical and social contexts, provide a better opportunity to locate the forces and mechanisms at play than those limited to individual people or generations. They may also provide a basis for more informed political action.

As revealed from the pictures drawn here of the three generations, the meanings attached to experiences of disability have changed over time, and reflect at least partially dominant modes of thought in the respective generations. This relates to the motivation for Mannheim's early conceptualization of generation, that of generational differences in values and ideas. There is no doubt that the individualization of identities reflected in the youngest generation in our study is linked to more general processes of reflexivity and individualization in late modern society (Giddens 1991, Beck 1991). This represents emancipation from social and cultural restriction and control, but also suggests new forms of vulnerability and risk. To analyze the links between dominant values and the definition of self provides important insights, not only to individual social orientation but also to the possibilities of new forms of social organization.

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