

PAPER IN PROGRESS

PERSONAL STORIES OF SOME FORMER INMATES OF A NORTH-NORWEGIAN INSTITUTION FOR PEOPLE WITH INTELLECTUAL LEARNING DISABILITIES; EXPERIENCE, STORIES AND PERSPEKTIV

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Abstract

In Norway institutionalised care for people with intellectual disabilities is a closed chapter. The aim of this paper is to describe and discuss the living conditions of people with intellectual disabilities at Trastad Gård, an institution for people with intellectual disabilities. Trastad Gård was established in 1954 and closed down in 1990.

The paper is based on data collected by use of qualitative interviews. 15 informants who lived permanently at Trastad Gård were interviewed. The interviews were recorded on video tapes. Some stories of four informants will however be made use of.

Findings indicate that most of the daily experiences of the informants may be understood in terms of discipline and domination from the caretakers. Most of the informants seemed not to be upset about the way they were treated in the institution. This lack of reaction on the part of some of the informants may be understood in terms of “socialisation”, “devaluation”, “social representation” and “cultural understandings”. Our informants seem to have internalised a social understanding of them selves as less worth and that seemed to have accounted for adamant responses when narrating stories about their past.

INTRODUCTION

This paper is the result of a joint project known as “Life at Trastad” and initiated by the Department of Social Education (Vernepleierutdanningen), Harstad University College and Trastad Gallery (Trastad Samlinger)¹. The project was started in the autumn of 2004 and has as its main goal to document everyday life experiences or living conditions at Trastad, the first and largest central institution for people with intellectual disabilities in North- Norway.

Even though Norway has half a century history of institutional care, little has been done to systematically capture the stories of former inmates of institutions for people with intellectual disabilities. One of the closest Norwegian studies that involved narrating the treatment of people under institutional care is “I know I’m different, but not always”² by Marit Sundet (1997). In northern Norway the time to reconstruct or open this very important

¹ In Norwegian: “Trastad Samlinger”. “Trastad Gård” or only “Trastad” is the name of a former large North Norwegian institution where people with learning disabilities were placed and taken care of.

historic window is limited. This is because many of the inmates of Trastad are getting older and may soon not be able to tell their stories.

A retrospective approach is adopted in this study. It involves presenting and analysing information narrated by some of the former inmates of Trastad Central Institution. Their experiences in the institution including activities in the wards, recreation, friendship relations, services at their disposal and reflections on how they were treated will be focused.

We have chosen to use terms that were common at the time our informants lived at Trastad. This is not because we are unaware of the implications of using such concepts today, but that use of original concepts paints true historical pictures. The term “patients” was for example used to describe persons with intellectual disabilities who were admitted to Trastad. Between 1969 and 1970 Norwegians with intellectual disabilities were referred to as “åndssvake”. The English term in use during the same period was “retarded”. The term will be used as a synonym to the Norwegian expression “åndssvake”. In Norway the term “retarded” was used to categorise people with less than 55 Intelligence Quotient (IQ). According to Folkestad (2004), these were people considered as unable to learn and were therefore sent to institutions to be nursed, cared and protected.

The rest of the paper provides a brief account of the history of Trastad institution. This will be followed by the method for data collection. Data and its analysis will then be presented. The paper will be concluded with a short summary.

Historical background

Trastad Gård came into existence as a response to the lack of governmental involvement in provision of institutional care for people with intellectual disabilities in northern Norway. Initiative from the church supported by the state made room for the mobilisation of local resources in the form of appeals for funds. The locals in North-Norway contributed large sums of money for the establishment of Trastad. When Trastad was established as an institution for “mentally retarded” this form of care delivery was considered as a modern model. It was with great enthusiasm when Trastad opened its first ward. Trastad

² The Norwegian title is: ”Jeg vet jeg er annerledes, men ikke bestandig”.

grew very fast and after a few years hosted 375 patients. In the early 1970-ties governmental reports revealed many unworthy living conditions in the institutions. The institutions themselves were unable to manage the problems so on the 1st of January 1991 the idea and practice of institutional care in Norway was abandoned. Care or the responsibility for people with intellectual disability was transferred to the local communities (Johansen 1996).

METHOD

The method adopted in this research meant to capture and discuss the experiences of some former inmates of Trastad institution is biographical interviews. According to Denzin (2000:539), a biographical interview or life history is any retrospective account by the individual if his life in whole or part, in written or oral form, that has been elicited or prompted by another person. This method allows the informant to present things as he or she understands it. While Thagaard (2003) views this interview form as one that captures the subjective experiences of informants. Kvale (2002) is of the view that this interview form makes it possible for the informants to tell their stories without interferences from the researcher. The method was traditionally used by the “Chicago school” in researches on transsexual and disabled people form the 1920s (Bogdan/Taylor 1998).

Fifteen former inmates of Trastad institution were interviewed using this interview form. These are “mentally retarded” people who lived at Trastad from 1954 to the end of 1990. Ten of them still live in the local community where the institution was located. The other informants now live in other communities in northern Norway. Information about the whereabouts of these informants was obtained from former employees of Trastad.

With the use of interview guides, informants were asked to comment among others on questions regarding why they were admitted to Trastad, their positive and negative experiences, and whether they would like to move back into the institution. The interviews were recorded on videotapes. A video camera was mounted in the stand in the rooms that the interviews were conducted. Where the rooms were dark, extra lights were used to enhance the filming. Each interview section took between thirty to fifty minutes. Permission to interview and film the informants were sought prior to the interview process.

We made sure to establish the rapport, explain clearly the reasons for the interviews and their future use, before starting interviews. Efforts were also made to limit

communication problems leading for example to a “yes saying” which according to Tøssebro (1989), is common during interviews with people with intellectual disabilities. This was done by asking short, clear and repeated questions, and also making sure informants understood the questions we posed.

PRESENTATION OF DATA

As indicated earlier, this chapter is still at its early stage just like the project itself. Some personal stories of four informants with the fictive names Tor, Mary, Eva and Ruth will be presented at this stage.

Tor who is a man in his early fifties and lives in a four-man apartment with other former inmates told us that he came to Trastad when he was between 13 and 14. At Trastad Tor lived in different wards. The first time we met Tor we was told that he could be difficult and tiresome to be with because he was stubborn and besides he used to make comments on what others said and did. Tor had meanings and he cared. This was understood as problematic from the helper’s side.

Mary is a woman in her forties. She has the Down syndrome diagnosis with a slight hearing difficulty. Mary had little contact with her family. She was of the view that she was not happy with the arrangement which makes it imperative on parents to deliver their children to institutions for upbringing.

Eva is a lady in her fifties. She came to Trastad before her date of confirmation. She became known as a clincher. Eva told us she for a longer period was living together with 20 girls at Trastad. She however felt no sense of togetherness. She pointed out that some of the inmates even scared her. She also tells us that the caretakers had no time being together with her. She pointed out that she often kept to herself listening to music.

Ruth is a lady characterised as a firm lady. She is an outspoken person with a strong personality. She derived her self esteem from her working ability. She calls herself a “slogger”. Ruth speaks very fast, almost without breaks. Ruth tells us about her upbringing by the professionals at Trastad, which she consider to be rather strict, although she understand that they did what they did in her best interest.

Stories about the experiences of informants on arrival arrived at Trastad, upbringing/discipline, their relations with others and their attachment to the institution are

focused. Their stories on particular events or issues are presented in the form of dialogues as follows:

Tor's story - "Coming to Trastad"

Interviewer: Tor, do you remember when you came to Trastad?

Tor: *I came in, well.....I don't remember the year, but I remember I came, I came when I was...., I think I was 13 years when I came to Trastad.*

Interviewer: Yes, when were you born?

Tor:.....*in 1952.*

Interviewer: Do you remember how you came to Trastad?

Tor: *I travelled in "hurtigruten" (a passenger boat) together with my father. So he followed me, first to Harstad, and then to Pavilion 2³, and thenhe left for home, and then I lived for a short while in Pav.2, and then I was told to move and then I wondered where I was to move to.*

Interviewer: But when you first came to Trastad did you stay at Pav.2?

Tor: *Yes, it was the first time.*

Interviewer: How was it like being there?

Tor: *No, it was a....there was a lot of noise there; there were over 40 persons living there.*

Interviewer: 40 girls or?

Tor: *No, only boys, yes, in 2a..*

Interviewer: Do you remember the number of employees – staff?

Tor: *Yes/no, let me see, there were so many people working there. I'm not sure about the exact number but may be 12 people worked in 2a.*

Interviewer: Did you come to 2a when you were between 13 and 14 years old?

Tor: *Yes, I believe I was about 13 – 14 years old.*

Interviewer: What did you do during the day?

Tor: *No, what can I say,nothing. The first thing I did was to sit and play with toy bricks, like infants do, then when we got bored, we were allowed to draw, and if not we were allowed to be outdoors, but not to go to anywhere else.*

³ Some of the wards were named Pavilions and given number in the order they were built. These pavilions often had the letter a or b after their number. This indicated that one part of the pavilion was meant for girls and the other part for boys.

Interviewer: But, not to go anywhere, where? Around...?

Tor: *Yes, exactly, we were allowed to go down to the road, but not to go on visits without advanced notice, and in the weekends we were allowed to go to the kiosk to buy candy.*

Interviewer: Did you go visiting other people, Tor?

Tor: *No, I kept myself within 2a.*

Interviewer: Tor, you were only 14 – 15 year old in 2a. Did you feel homesick?

Tor: *No.*

Interviewer: Did you have visit from home?

Tor: (stuttering).....*ee, eeh, no*

Interviewer: Did you have contact with those at home?

Tor: *No*

Interviewer: It wasn't as easy to phone then as nowadays.

Tor: *I could think like that in between...*

Interviewer: Because it isn't that easy to be so young and being so far away from the parents.

Tor: *No, clearly.*

Interviewer: Was there anyone in 2a you felt you could talk to and who took extra care of you?

Tor: *NO, there was nobody ... no....*

Mary's Story – “Feeling Homesick”

Interviewer: Do you know why you came to Trastad?

Mary: *No, I don't remember.*

Interviewer: Do you remember who came with you?

Mary: *No, it was neither of them...*

Interviewer: When you came to Trastad, did you feel homesick; did you feel like going home?

Mary: *Yes, I felt homesick.*

Interviewer: Did you?

Mary: *Yes*

Interviewer: What did you do when you felt homesick?

Mary: *Then I went to my brother.*

Interviewer: Oh yes, where did your brother live?

Mary: *They lived in Oslo in Tønsberg⁴.*

Interviewer: Oh yes, Tønsberg, it is not a shortcut to Tønsberg!

Mary: *Oh no, it isn't that far. I missed them.*

Interviewer: But were you home in Lødingen every summer?

Mary: *They have forgotten to call me.*

Interviewer: Did they forget calling you?

Mary: *No, they.*

Interviewer: They forgot to call you?

Mary: *They forgot to call me, without, without keeping our agreement.*

Interviewer: Could you have phoned them?

Mary: *They have a lot to do.*

Interviewer: They have a lot to do, yes.

Mary: *Yes.*

Interviewer: Did you visit them at Lødingen in the summer

Mary: *I have been there.....*

Eva's story- "Living alone together"

Interviewer: ...else, what did you do inside the ward, in the living room for instance?

Eva: *Mostly I was sitting in my room, playing music, that's what I did. But what the others did, I don't know because they were in the common room, the room shared by all. So mostly I went by my self and played music. I felt a bit alone.*

Interviewer: In Pavilion 7b?

Eva: *Yes.*

Interviewer: ...even though there were so many people?

Eva: *Yes, but there were so many who had no clear thoughts to put it like that.*

Interviewer: You had no one to talk to?

Eva: *No.....and there were one who was impossible – she moved to Pav.8. She broke the window. I was terrified.....I sat mostly alone. Almost no one talked to me.*

Interviewer: What about the staff?

⁴ Tønsberg is a city about 2000 km. south of Trastad Gård.

Eva: *No those, they only went talking to the others. They didn't care about me sitting there.*

Ruth's Story- Upbringing/ discipline

Interviewer: We have heard stories about you having to walk up to the Horn⁵.

Ruth: *John sent me there whenever I was difficult or something like that, yes.*

Interviewer: What do you think of that?

Ruth: *No, it was ok. Once I kicked Peter in 1991, I had to walk up to the "Horn" I had to put on a pink rain coat, and John was to keep an eye on me all the time so that I did not sit down. When I came to the Horn I was supposed to turn around and go straight back down. It was winter and icy up on the mountain, and I slipped on the ice and nearly fell down, God how afraid I was, I could have fallen and beaten me to death, but I managed to go through.....*

Interviewer: What do you think of that?

Ruth: *No, I learned.....it was because I was to learn, I don't take this as a punishment or something like that, because I liked walking in the mountains so it was not any punishment.*

Interviewer: But after Pavilion 8, where did you move?

Ruth: *Then I moved down to Entrance A.*

Interviewer: Yes, how did you experience that?

Ruth: *No, it just... as a good thing, and I collected a lot of dirt in my bedroom, tin cans and stuff like that, and then we were on a trip to Gullsfjorden, and then they said to me that they would clean up and throw away my things, and I got an anxiety for several days, and then it was not done when we came back, and then I got this bad strange feeling inside of me, I thought they were going to throw all my things away. I lay in my bed at nights banging my head on the wall behind me and hoped to die, but I didn't, and then I had a lot of writing stuff. I took with me the ones I was most fond of to the forest and hid it in Myrestua (a hut), and then I was lucky that GS began as a Leader of the ward, and asked me if I would like to move to Entrance B, where I was to have my things alone, and there I told SB everything and she felt pity on me, and then I went up to "Speiderhytta"(another hut), and collected them envelopes.*

Interviewer: Did you find them?

⁵ The Horn is the name of a local mountain peak.

Ruth: *Yes, I found them, but they had begun to mould at the edges and things like that.*

Interviewer: Yes...

Ruth: *Yes, I found them and took them with me.*

Interviewer: Nobody threw away the things you had collected, in the end?

Ruth: *What?*

Interviewer: Nobody threw the things you had collected?

Ruth: *No, they told me at the end that I had to do it myself. I then threw the food boxes and the tin cans, and then they didn't, because they said there was a bad smell in my room because I stored food and paper.*

Interviewer: Did you agree in that?

Ruth: *Yes I did, but not my writing stuff and things like that, address books and the negatives and things like that, that I didn't agree upon.*

DISCUSSIONS

The interviews brought to the fore several important experiences. Four of these are to be discussed here. As indicated in the headings to the interviews these are: "Coming to Trastad", "Feeling Homesick", "Living together alone" and Upbringing/discipline. Together with information from other former inmates we will create a theoretical understanding of these experiences. To do so we will deploy the concepts of socialisation, social representation/cultural understanding and social domination.

Coming to Trastad

Our informants responded differently to questions about why they were admitted at Trastad Gård in the first place. One of the informants who came to Trastad at the age of twelve told us that she was brought to Trastad because she mistreated her cat. This behaviour was probably interpreted as unusual and warranted her admission at Trastad. Another reason for gaining admission to Trastad, according to another informant is his physical impairment. This informant who arrived at Trastad Gård at the age of four made it known that he was brought there because he had Cerebral Paresis. A third informant was in her 20`s when she first came to the institution, she told us that she was dangerous and therefore could not live at home. Although the informants respond differently about why they were admitted most of the

reasons assigned for being sent to Trastad seems to make the inmate responsible for being sent to an institution at a tender age. The practice of blaming the patient for actions that they have no control over only emphasise the significance of individual models in understanding how our informants were treated.

The stories told by our informants also points at the number tags that were allocated to them on arrival at Trastad. “My number was 2, was the response from one of our informants who lived longest in the institution. Not only did all of our informants remember that they had number tags put on their clothing’s, some even remembered the serial numbers of other “patients” or inmates. X had number 2 and Y was number 20 one informant told us. The number is an indication on when they were inscribed at Trastad Gård. All the inmates clothing were marked by this number. Linking numbers to names underscore the fact that they were first and foremost patients inscribed to a system that needed order. Their identity as humans came in the background as a result. Johnsen (2002) points out that formal systems often have a logic of their own in form of rules and routines created to make the system work properly, and inmates often is valued, as good or bad, on how they adopt to the system.

Other experiences on their arrival at Trastad centres on how they were accommodated. Tor remembered being allocated to a ward which was shared by forty other “patients”. Privacy was therefore out of the question. Eva is another informant whose story confirms the issue of lack of privacy at the wards. Eva mentioned that she had to retrieve to a corner in the common room to listen to music. This way of accommodating inmates also might be understood as a way of robbing them their self wealth. To do this the staff, even if they have only good intentions, need to have an understanding of the inmates as being less worth or inferior rest of the society. This devaluation (Wolfensberger 1992; Kristiansen 1994) put into action by the accommodation, patient numbers and other arrangements is likely to be infected also to the inmates and their self understanding. According to Burns (1982) it is likely that the surroundings over time will have a great impact on the self esteem. Thus it is likely that many of the patients of Trastad over time have internalised an understanding of themselves as less worth. They start to devaluate themselves.

“Feeling Homesick”

According to the informants the feeling of homesickness was an integral part of being inscribed to and having to live their life at Trastad. The point is when parents deposit the children at Trastad they were not supposed to pledge any close contact with their children. So even if one is feeling homesick, one can do little to solve the problem. While the use of telephones may have minimised the homesickness, telephones were uncommon in many homes in the seventies. Besides the institution controlled access to phones in the ward. The inmates had to ask of permission if they wanted to use it, and the staff had to allow them the use and also had to help in use. This also led to the staff to be present during the call, listening to the conversation.

We were told that it was difficult to maintain contact with their parents at home. Very little, if any, indicates that the institution was keen on establishing this contact. This also can explain the lack of contact many of our informants had with their parents and brothers/ sisters.

No matter what reasons, the outcome is the same; many of our informants lost already as children the contact with their nearest family. Research indicates, that children who are separated from parents and placed under institutional care at early ages, are often prone to psychological imbalances in later life (Santavirta 2005, Eikeland, 2005). Karl Jacobsen (1998) also argues that intellectually learning disabled people may have other interpretations of situations, but their emotional expressions are the same as all human beings.

Thus, when Tor told us he felt sad when the parents left him at Trastad Gård, this feeling of being left alone was real. The loss felt by losing contact with parents, sisters and brothers doesn't go away just because of the intellectual learning difficulty. He is not emotional disabled.

“Living together alone”

Life in the institution, according to some of our informants, is that of keeping to oneself. They had no one to talk to, nor by the other inmates nor by the staff. “Living together alone” is a way to describe this phenomena. Since they lived collectively in a ward one would expect a closer relationship between the roommates. This feeling of loneliness or having no

one to talk with is not limited to the roommates but also to the caretakers. As indicated in the interviews, some experience being overlooked by some of the care takers. This also means that inmates who were afraid of other inmates not necessarily had anyone to tell their fear about. Despite the fact that there in many of the large wards were windows between the kitchen and the living rooms they could be kept under surveillance, feelings of insecurity may have been the inevitable. These windows might be understood in terms of Foucault's (1979) panopticon. It was an effective way of controlling the patients' behaviour. So instead of being comforted when lonely they were given corrections when behaving badly. In the absence of comfort perhaps corrections might have been a tolerable substitute.

Upbringing/discipline

Our informants had vivid memories on how they were brought up at Trastad and the disciplinary measures that were adopted. The upbringing involved socialising them into the activities of daily living, for example introducing them to Christianity. Morning devotion was compulsory and all the inmates were expected to participate in it. The idea of compulsory participation in morning devotion must be understood in terms of ownership or the professional background of those who established the institution. The institution was owned and managed by the Episcopal district of northern Norway, and the institutions first director, Johannes Gilleberg, was a priest from Hammerfest and the early nurses, were Diakons. During the process of preparing the interviews, we found a circular letter from 1957 written by one of the Diakons to the staff at Trastad Gård. The circular has as a heading: *"To those of you who nurse the children"*. The Diakon writes further: *"We want the children to learn their morning prayer, so sing grace before and after meals"*. And further on *"When you have put the children to bed, then read their evening prayer"* (Our translation). Every morning at nine o'clock there was a devotion. It is possible to view this routine as a result of the Christian wanting to spread the word. This could also be viewed in terms of the desire to give equal human status to the "mentally retarded" children in the institution. Regardless of the good intentions, most of our informants made it clear that they did not enjoy the obligatory participation in morning devotion, but they had to be there anyway. Inmates were supposed to participate in the daily prayer meetings and church activities. The informants noted that they were expected to follow the numerous rules at the church and that made some of them

refuse to attend morning devotions at times. As it was common at the time, defaulters faced disciplinary actions. One of the disciplinary measures the informants recollected for refusing to attend morning devotions was being locked up in their bedrooms during the morning prayers. So, the idea of treating them as other human beings by offering them morning devotions became because of the restrictions followed to those who denied taking part of this just another way to being told their place in the world as inferior the staff. Other disciplinary measures adopted were at times being tied to beds or denied the chance to go on visits. What kind of disciplinary actions used depended on the staff present their view of the “crime”.

The maltreatment narrated by our informants however did not seem to have sown any bitter feelings in them. Informants expressed their views about their ordeals without a spectre of anger in their voices. This may indicate the extent of the socialisation process they have been through. Most of them came to Trastad as children and therefore their primary socialisation began at Trastad. They were socialised into accepting that punishment was the way of correcting bad behaviour, and rewards, for good behaviour. Their apparently emotionally calm reactions to questions that reminded them of their past woes may be understood in terms of how they distanced themselves from the past. After all, they no longer live under such circumstances. As one informant expressed, “this is how things were back then”. In other words, this is how every patient at Trastad was treated, and therefore their apparent acceptance of their devalued status.

The concept of social representation which was introduced by Serge Moscovici (in Cahib/Orfali 1996) may also through light on the reactions of our informants regarding questions on how they were treated at Trastad. Social representation has to do with how people construct an understanding of social phenomena. Social representation makes it possible to place people in social categories. The concepts “social representation” which also provides cultural understanding of social phenomena therefore enables us to understand the passive behaviour of our informants. Being passive might have been the only socially representative response to repressive behaviour from “superiors”. Put differently, the only cultural understanding they had as inmates who were often made to take instructions from the caretakers, made them respond accordingly. Social representation therefore made domination of inmates by the caretakers possible. This also has to do with the types of force that were put to use. Our informants pointed out that they were subjected to corporal punishment by the

staff. Others were forced to stay in bed when they were reluctant to participate for example in morning devotion. Stories of tying them to the bed and the use of strict house rules are common ways of forcing them into obedience. "*It was a hard regime,*" one of our informants said.

When our informants told us about being exposed to the use of force it is possible to understand this as private or ad hoc "solutions". This is to say solutions that have no legal support. Maybe these "solutions" were carried out without others knowing of it. But at least some of the infringements for example in the case where Ruth had to walk up to the mountain took place in the presence of other staff members and cannot be considered as a private act. The point is "it made no difference to protest," we were told. "If you tried to argue against the authority of the staff, you were punished." The staff in a way determined all the terms for behaviour in the institution. This is to say that the staff decided what the inmates should do from the time they get out of bed to bedtime. When Ruth told us about her displeasure due to the staff's decision to take her plastic bag with her personal belongings from her, she was not at the same time telling us about the desire to revenge or hurt them. Her reaction of banging her head against the wall, hoping to die, was simply an expression of powerlessness. Often, the behaviour of people with learning disabilities is explained in terms of their impairment. This is paradoxical, according to Sundet (1997). For Sundet, maltreatment, lack of intimacy or other forms of reactions have much to say in the understanding of the behaviour of inmates of institutions.

SUMMARY

The paper is about the former inmates of Trastad Gård (1954-1995), a closed down institution for retarded people in Northern Norway. We have interviewed fifteen former inmates, who came to Trastad as children and teenagers. Four main issues of importance to a biographical understanding of their lives at Trastad are discussed. These include issues about their coming to the institution, their feelings of homesickness, their loneliness, and upbringing. These were deduced from video interviews conducted at the Trastad museum and the homes of some of the informants. By presenting some of the stories we have been told we have highlighted some parts of the newer Norwegian social history. Efforts were made to

provide a theoretical understanding of how the inmates were treated and their silent acceptance of treatments emitted to them in the institution. This was done by deploying the concepts of socialisation, social representation/cultural understanding and social domination by use of force.

People with intellectual or learning difficulties are often not used to expressing themselves by words or pen. It is thus up to others to ensure that they have the opportunity to tell their own stories and make their contributions available to society. Due to imbalances in power relations we as storywriters are in a position to transform stories about their lives as they present it to how we think their stories should be told. When writing the social history of people with learning difficulties, we as storywriters face a challenge in presenting the stories as they are told to avoid alienating the storytellers. History writing is important as a means of shaping present and future care provision.

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