

Study of a life-story

The life-story of Olaf H. was constructed from interviews with his parents, professional carers and those responsible for his living arrangements and day-care (approx. 7 hours). Some names have been changed.

The study is structured as follows:

1. Overview of Olaf's life with the relevant points following the demands made. (p1-3)
2. Succinct description of various areas of life: the phases "at home", "in Alsterdorf" and where possible, the present life situation.
3. Answers to two important questions: Which risks is this person exposed to? and With regard to legislation and finance, what would we like to change?

1. Life experience

Olaf H. is born on 22.10.1966 in Hamburg. His parents are Karin and Rudolf H. and they live in Hamburg. The family also has another son, Marcus H., who is born in 1973.

Olaf's mother is 19 and his father 22 years old when Olaf is born. There are complications during the artificially induced birth. The mother said the birth was "mucked up." Later, the medical records relating to the birth cannot be found. The parents decide not to make a police report. The family lives in a room at the home of Mrs. H.'s mother.

It gradually becomes clear that something is wrong with Olaf. He has a delayed development and at the age of two, learning disabilities, physical disabilities and a spastic paralysis are diagnosed at a Social Paediatric Institute. Olaf is prescribed weekly physiotherapy treatment. For this treatment, Olaf's parents must visit the practice with their son. Occasionally, the treatment has to be discontinued, as Olaf is "unapproachable". He screams and charges about and is fixated on his mother.

When Olaf is four years old he is visited for the first and only time by an official from the child welfare authority, who informs the family that they are entitled to care benefits (120 German Marks). This figure is reduced at a later date as the father, a plumber, had earned too much. The family receive vouchers instead. Apparently the mother had first contacted the child welfare authority on several occasions. She explains that she always felt embarrassed and the parents find their treatment very hurtful.

When Olaf is four and a half years old he takes his first steps. The health insurance company begins to complain about the ongoing physiotherapy payments. An independent examining doctor is employed and recommends the continuation of treatment.

Olaf's mother becomes pregnant for the second time. This child is also disabled, although not as severely as Olaf. Mrs. H. is sceptical about this second pregnancy and

as a result the doctor requests the records of the first birth. These cannot be found and there are no grounds for a decision about the pregnancy.

The family moves into their own home. Mrs. H. contacts the German Red Cross in order to have a nursery place for her son. She is advised of the nearby special nursery. This nursery refuses to accept her son, according to Mrs. H., as they only accept children from better-off families. The second special nursery is about 10km away from their home. Olaf receives a place there and the German Red Cross pays for the transport costs.

The other residents of the house in which the family live are described by Mrs. H. in a positive light. They support Mrs. H. and there were never any complaints registered at the housing association "SAGA" about the noisy boy who banged against radiator pipes and pulled curtains down.

In 1975, when Olaf is nine years old the head teacher of a newly-built special school contacts the family and offers him a place at the school. Mrs. H. says that the education authority had never contacted her, not even when Olaf would normally have started school at six.

The doctor treating Olaf advises Mrs. H. that her son could be sent for treatment at a health resort. Olaf's first visit to a health resort is a traumatic experience for his parents. When they meet Olaf, he is completely changed and does not recognise his parents, hits his head on the floor and has forgotten all the words and half-sentences which he learned with his mother. Mrs. H. explains, that the parents were not brave enough to protest or complain. No one else complained, either after or during the treatment at the health resort.

Olaf H. has no friends; he has contact with his relatives who come to visit the family. He regularly goes on holiday with his family to their campsite. The family also goes on holiday abroad with their campervan. During their journey the family have many bad experiences with hotels and restaurants.

According to Mrs. H., Olaf received little support in the school he attended. Although the staff were good, the personnel changed frequently. The school complained that Olaf was intolerable in the group. He threw objects. His group has eight pupils and two adults. During this period at school, Olaf breaks his arm twice.

During the crisis Olaf's mother suffers a nervous breakdown and his father brings him to Alsterdorf and without waiting for a decision, leaves his son there. Olaf had been treated there for four weeks previously in the medical outpatients unit. In February 1983 Olaf is officially admitted, initially to the psychiatric unit. Mrs. H. visits her son on a daily basis. After five weeks Mrs. H. is told by the doctor in charge that her son will not be returning home. Mrs. H. should turn her attention to her second son.

At this stage, Olaf already visits his future group home from time to time. The carers there are enthusiastic about him and he feels at home. His parents also agree that Olaf join the group home.

As a result of a consultation with a doctor who, according to the mother made a mistake, in 1983 both of Olaf's ankle joints are removed and his legs are in plaster for six months. In passing, his mother explained how the doctors removed the operation support needles without anaesthetic. From 1986 onwards, Olaf uses a wheelchair. He requires an "active" wheelchair so that he is able to move more freely. As a result of Olaf's condition the wheelchair frequently has to be repaired and replaced. The family begin a long battle with the health insurance company over the wheelchair.

With the exception of eating and drinking, Olaf requires complete support and care. The costs of the physiotherapy, which is still necessary, have to be carried in part by his parents. Olaf has the opportunity to take part in swimming therapy but this is not possible because the health insurance company fails to cover the costs of a pair of special swimming trunks. For a short time, the family even have to battle for the money for nappies. Donations make it possible for him to take part in a riding for the disabled programme but continuous participation fails, as the transport costs cannot be met.

In 1987 Olaf leaves Alsterdorf's own special school. His school education has come to an end. Olaf now has no regular day-care and is constantly in the group home. He receives support for only two hours, twice a week. This is the situation until 1996. Other parents whose children are in a similar situation contact the relevant authorities with their lawyers. They receive a place in a day-centre at a second location. At this time, Alsterdorf had not yet developed such support systems.

In 1985, Olaf is moved from the group home he has been in until now to another, the unit for the "difficult", the "runaways" and those with challenging behaviour, where in the case of most residents a decision was made to admit them and they can also strapped down. Mrs. H. explains that she had complained about this decision to both the house management and the Alsterdorf management but without success. In the previous group home, Olaf was happy, whereas in the new home he has to come to terms with difficulties in settling in.

In the group home he meets other residents who, through their behaviour and noisiness aggravate each other and also disrupt Olaf, leading him to disruptive behaviour. Olaf's behaviour is noticeably more disruptive: he throws objects around him. Afterwards he calms down and sleeps.

Olaf has a single room with a bed and an inbuilt wardrobe. His wheelchair is also in the room. The only free-time activities are the yearly one-week holiday and occasional walks and visits at the weekend. His parents visit him regularly and he visits them every second weekend. The carers in the group home and Olaf's parents talk intensively about Olaf's needs. The situation becomes more relaxed in 1996, when Olaf is offered day-care.

Olaf further develops his passion for travelling. He enjoys travelling by train, bus, boat and car etc. He has no friends.

In 2002, Olaf leaves the central Alsterdorf site and moves into a flat with three other people in a nearby part of the city. He has his own room in the large, light flat and importantly more interest from his carers. His horizon is also broadening. The move

was carefully planned and carried out. As Olaf is limited in what he can articulate, it is necessary for his carers to carefully assess his wishes.

He is now able to travel by bus to the day-centre twice a day. He receives no financial support for his travel costs.

2. Schematic presentation

2.1. School

Olaf could not take nursery or school places for granted. His mother had to organise a place herself. In one nursery he is rejected: the family suspect discrimination.

According to his mother, the range of support in his first school was poor. It was not an integrated school, as they did not exist in Hamburg at this time. There were obviously also significant problems in this school, which the teachers were unable to deal with. Olaf was classified as intolerable. After moving into Alsterdorf, Olaf attended a special school for a further four years until he was 21 years old. This school aimed and aims to provide targeted support for pupils with learning difficulties.

2.2. Work

After leaving school Olaf went nine years without receiving day-care support. As a result of the consequences of his disability he was never considered suitable for work in a disabled persons workshop. This was never seriously discussed. The profile demanded by such workshops does not correlate with people like Olaf.

After the Alsterdorf Foundation established a large number of day-care centres in the mid-nineties, Olaf was also offered regular day-care, be it in the same house where he lived. The continuation of day-care support was questioned when Olaf moved house in 2002 as financial support for his transport could not be found. Olaf clearly enjoys the activities in the day-centre. He is able to meet other people in his area and experiences this as enriching. He does not foresee having his own income and this is also not planned.

2.3. Accommodation

Olaf spent his first 17 years with his parents. His mother admits that she was always felt embarrassed because of her disabled children, but on the other hand both parents cared for their children deeply. The move to their own home, according to the parents did not lead to open discrimination in the area. Rather, the neighbours seemed understanding and supportive, although Olaf's behaviour made him stand out. The family lived in council housing flats.

To be noted is the (almost) complete failure of the authorities to provide support for the family (nursery, school, benefits). The services had to be fought for. They could not be taken for granted. The move into Alsterdorf was the logical consequence and dramatically marked the beginning of an isolation process. This could also not be halted within such an institution. After leaving school, Olaf had to leave the group home where he had felt at home and was moved to a "difficult" group where he received no day-care in a separate location. Protests from his mother were futile: she was told to tie the line. At the end of the nineties, new quality assessments and

individual perspective planning led to a targeted search for alternative accommodation.

In 2002, as a result of having asked himself the question: “what does this man want?” over a long period, Olaf left the central Alsterdorf site after 20 years and moved into his “own” home in a neighbouring part of the city with three other people.

2.4. Free-time

Olaf’s parents spend a lot of their spare time with their children, but describe on the other hand the negative experiences they have had as a result of their disabilities. Whilst resident in Alsterdorf, Olaf was dependent on the free-time activities offered by his group home, which were mainly walks and bus trips at the weekend as well as a one week holiday each year. The organisation of his free-time has not yet changed in his new home.

2.5. Mobility

Olaf has been wheelchair bound since 1983 as a result of the operation on both legs. The fight for the provision of his wheelchair through the health insurance company fills his records. The attitude of the health insurance company towards Olaf was particularly restrictive and unhelpful. For some time Olaf had to go without a suitable wheelchair and was severely restricted in his freedom of movement.

In his new home, the wheelchair is very important for him as it enables him to explore the area, which interests Olaf very much.

2.6. Health

Olaf’s birth was described by his mother as “mucked up”. The complications probably caused the disability and its consequences. Later the records could not be found. Nobody saw cause for a police report, even the doctors. Otherwise Mrs. H. describes the doctors who treated Olaf in his childhood as very caring and helpful. Mrs. H. has to fight for Olaf’s right to physiotherapy, often alone.

When Olaf is admitted to Alsterdorf, the responsible doctor imposes her will, although the family agree to the admittance, as they feel overtaxed.

The operation in 1983 and following treatment are not considered by Olaf’s mother to have been the appropriate measures. From this point on constant care with orthopaedic aids is necessary which must be fought for from the health insurance company. The same is the case for therapy.

Healthcare was carried out by Alsterdorf doctors until the beginning of the nineties. Since then the residents have had the right to choose their own doctor.

2.7. Family

Olaf is unusually lucky to be part of a family that has remained intact. Since his admittance to Alsterdorf at the age of 17 he has visited his family every second weekend from Friday to Monday. His parents also visit him in the intervening period. He has not started his own family.

3. Important questions

3.1. Risks

? As a result of a lack of agreement between organisations providing rehabilitation care, there is often an unbearable delay in the provision of care in the form of necessary therapy and aids, but also in the provision of transport costs etc. This is still the case today.

? On the basis of his wide-ranging care needs, Olaf runs the risk of sooner or later being admitted to a care-home. The danger here is that the assistance he requires for participation in society; the aim of rehabilitation in care of the disabled, would no longer be available.

? Falling standards in care of the disabled pose the danger that Olaf will once again be more dependent on care structures where his individual development chances may be restricted.

3.2. Legal and financial arrangements that must be changed:

? Support for individuals with disabilities must be combined in a single assistance and treatment concept/plan seen from different perspectives (medical-therapeutic, social-pedagogical, psychological etc.)

? The source of finance for all necessary measures must be clear during the formulating of any such plan, so that delays and evasions of those carrying the costs of treatment can be avoided.

? Necessary financial measures must be allocated on an individual basis. In order for this to be possible, models of a personal budget must be developed.

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Maas

Protestant Foundation "Alsterdorf"

Hamburg

Translated by

Heather Stansfield

Horner Weg 264

22111 Hamburg

040/65993566

Heather.Stansfield@web.de

CASE STUDY Rauhes Haus Hamburg

Although our client has agreed that we would publish his data we have decided not to publish his personal and family matters. We have also changed his name and his age.

References: reports and interviews

Boris, 33 years old, male.

Boris came into a children's home when he was 7 years old. He attended a special school for children with learning disabilities.

When he was 12 years old Boris was moved to another institution because of his challenging behavior.

With 17 years Boris was committed to a psychiatry hospital for five months due to challenging behavior. In the hospital the learning disability was confirmed. Further an emotional disability was diagnosed.

After leaving the special school, Boris worked in a sheltered workshop in the kitchen, but he often refused to work. The staff in the sheltered workshop was not skilled to deal with emotional disability. Boris wished to live more independently.

To prevent Boris' commitment to a closed psychiatry, Boris' guardian of the youth welfare department consulted the Rauhes Haus in Hamburg. The Rauhes Haus is well known for its supports for people who fail in the firm structures of other service-providing organisations.

Boris was 19 years old when he moved into a group-home of the Rauhes Haus where he lived with four other persons. In the first two years he often had conflicts with the staff and flatmates and outbursts of rage.

When he was continuously supported by a personal assistant who had a therapeutic background he started to take on responsibility. He began to reflect on the conflicts and, with support, he began to strive for constructive solutions. He became more independent in organizing his every day life. Boris still needed assistance for dealing with money, for managing official contacts and for searching a job. He likes music and literature, his greatest wish is to become a library assistant.

He has completed several placements and is very motivated to work and to learn. Due to the fact that Boris is a 'borderline case' between learning and emotional disability the support he applied for were declined (e.g. work assistance).

In 1997, Boris moved to an own apartment. There he got 15 hours weekly pedagogical support (PBW). Tasks of this support were:

Support in fulfilling the hiring contract

Help in organizing his every day life

Advice and support in financial matters

Support in and partial take-over in official matters

Support in finding work or a training

Support and advice in the psychosocial area

Advice and support in the realization of his lifestyle

The support is respectively allowed for a half year and must respectively be applied for again.

Until 2001, his the support was reduced to 6 hours weekly. In this year Boris worked in a rehabilitation-project. His social network increased because of the contacts he made in the culture-club. In leisure time Boris took part in a musical group and worked in the culture club's homo café. At the end of this year he became jobless again.

Boris still had financial difficulties and he didn't take care for his apartment. With his pedagogical support, the PBW, Boris applied for a cleaning service but his request was declined. In the following the pedagogical support applied for 8 hours support weekly. To check the application the health department carried out a one-hour assessment and recommended a cleaning service. Nevertheless, Boris received only 6 hours of pedagogical support per week. After sending a complaint letter (with support) he was allowed to engage once a cleaning service for 4 hours. It took another letter of protest and another half year until Boris was able to engage a regular cleaning service. It needed again some weeks before an appropriate service was found.

Again with support of the PBW Boris was able to apply for legal guardianship for finances and official matters. It took until 2002 that Boris got this legal support. In their reports Boris pedagogical assistants repeatedly pointed out that important requirements of his care plan were not fulfilled. The staff had to pay attention to hygienic and financial problems (electricity and telephone had nearly been cut off) and had no time to support Boris to find a job.

In 2003, Boris returned into a group-home and applied for a place in a sheltered workshop.

To understand this case study we would like to give some explanations on the German support system. The basic idea is a system-theoretical model, based on diagnoses. We criticize the system which classify people in strict categories.

Childhood / School-system: Some regular schools integrate children with disabilities. Further there is a variety of special schools (for physical disabled children, children with learning disabilities, with behavior problems, children with sensory disorders). We have a different legislation for children with disabilities than for children without disabilities.

Adulthood:

There are different rehabilitation support systems for adults with learning disabilities, adults with emotional disabilities, adults with sensory disorders, adults with physical disabilities. The care is payed by another system, the insurance companies.

The support can be provided residential or non-residential/individualised. For people with learning disabilities residential services are provided in a group home, in a huge institution or a psychiatric hospital.

“Non-residential” services are provided to persons who live in their own flat. Thus, only people who are or are expected to be able to live independently in a flat are supported by non-residential services.

As a ‘borderline case’ between learning- and emotional disability Boris experienced again and again that he doesn’t fit into the system and accordingly doesn’t get adequate support. Even when he was a child and a teenager the professionals who acted according to the system-theoretical approach, came to the conclusion: “Boris didn’t fit in our system.” Due to very negative experiences during his childhood Boris had no resilience and concluded: “I am not okay, I am good-for-nothing.” By challenging behavior he expressed that his wishes and self-determination were denied.

Boris told us: “In the Rauhes Haus group-home it was the first time that I was treated as an adult and that someone encouraged me and listened what I want”. With the empowerment of his personal assistant he was able to reflect his problems. He became more and more self-confident and self-determined.

Boris would have been able to live permanently in his own apartment. But the non-residential services in Hamburg are also working according to the system theoretical model. As an alternative to the group homes-groups, non-residential services are only available for people with learning disabilities who can look after their basic needs. The lack of interfaces which would have been necessary to deal with Boris’ different demands, caused retardations and prevent joint actions. This had a negative effect on the efficiency of support and Boris’ steadiness.

A solution would have been the following: A service which would guarantee personnel continuity and would develop therapeutical support via networking. To handle with demands of the every day life, e.g. cleaning and tidying, support should be provided. All services must be easy accessible (legal assistance, cleaning assistance).

The non-residential service system could not provide permanently the minimum of support which Boris needs to feel safe and protected. But reliability and safety are requirements to live independently, especially for people with a learning disability. Protection and safety were reduced by the system. (The bigger the success the less the support).

Personal stress results from the duty to report on progresses in the personal development every 4 – 6 month in order to get services further on, although the disability is permanent. To avoid this Boris applied for a group home place and a job in a sheltered workshop. With this decision he integrated himself into the system-theoretical model in order to get constant support. Boris has a lot of potential but instead of being promoted he has been weakened again by the support system.

Ursula Uderstadt
Michael Tüllmann

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