

Swiss National Association
of and for the Blind (SNAB)

Deafblindness in Switzerland

Facing up to the facts

A publication on the study
“The living circumstances of deafblind people at
different stages of their lives in Switzerland”

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1. When the senses no longer interact

Stefan Spring

Since the mid 19th century, enlightened people have been giving thought to disabilities. What is normal and what is outside the norm? In the past a variety of answers were given to these questions and, fortunately, most of these answers can now be disregarded. Superstitious ideas about disability being the work of the devil, sanctimonious accusations of guilt or the explanation that disability is a test sent by God, are rarely encountered nowadays. The widespread practice of excluding people with disabilities from public life has also largely disappeared. However, the fact that there have been and will still be setbacks in this area should prompt us to take a cautious approach, in particular when we as people affected by a disability or as experts in the field believe that we have definitely identified the right service for people with disabilities.

Over the last 50 years, rapid progress has been made in the field of medicine in Europe, including new possibilities for surgical treatment and new technical aids to help people with disabilities in their everyday life. Medical research has also influenced our image of what a normally functioning person is like. Normality is when the human body works smoothly. Therefore, it has become clear that dysfunctions and impairments are "illnesses" and represent a problem if they cannot be treated or cured. Against this background, deafblindness has been understood as one of the consequences of impaired hearing combined with the consequences of impaired vision. Until the end of the 20th century, this was also clear from the way the words were written: "deaf-blindness" or "hearing/visual impairment". Today the medical treatment for deafblind people still involves a dual approach. There are ophthalmologists and eye hospitals and alongside them there are ear, nose and throat specialists and the corresponding clinics.

There are also social insurance systems that are prepared, on the basis of visual impairments that have been diagnosed by doctors, to help offset the costs of care, schooling, advice and support. The same but totally separate facilities are available to compensate for the consequences of a hearing impairment. People who are unable to work as a result of an impairment of this kind receive only a modest level of benefit, which amounts to between 20 and 40% of the average income in Switzerland.

But how is it possible to live if both distance senses¹ have limited functionality when compared with a "normally functioning person"? What happens when the senses stop interacting and when the possibility of seeing to compensate for hearing loss and hearing to compensate for loss of vision has gone? What if in this case we understand the word "disability" literally, as a situation in which life and everyday activities are "disabled"?

Interestingly (or is it a disgrace?), in Switzerland and throughout Europe, only a few

¹ Sight and hearing are distance senses which are used for monitoring and connecting with the material world and with other people and for participating in cultural and social life. In contrast, touch, smell and taste are referred to as "close senses".

scientific studies on deafblindness have so far been produced. A master's degree dissertation² was written in Switzerland in 1984 on some aspects of the life of a small number of deafblind people.

Across Europe it is true that there have been several studies on the situation of and support for people who are born deafblind, but only a few smaller-scale studies have been carried out which look at the living circumstances of the majority of deafblind people. These are the people who have been confronted with the deterioration or loss of vision and hearing during their working life or in old age. This lack of scientific investigations corresponds with the trend of focusing research on children and young people, which can also be seen in the field of remedial and special needs education. In contrast, very little effort has and still is being made to evaluate more closely the living circumstances of adults who are affected by this condition.

In order to improve the support for and understanding of people suffering from deafblindness, the Swiss National Association of and for the Blind (SNAB) commissioned the research and development department of the University of Applied Sciences of Special Needs Education (HfH) in Zurich to carry out an investigation on a national scale into the living circumstances of deafblind people. For the first time, it has been possible to complete an in-depth study, as a result of funding from the Swiss National Science Foundation (SNSF).

The results of the study "The living circumstances of hearing and visually impaired and deafblind people at different stages of their lives in Switzerland" are both encouraging and alarming. An external, neutral and scientific perspective gives us a better understanding of the living circumstances of deafblind people and those around them. This study represents a milestone in the training of specialist staff and the strategic focusing of outpatient and inpatient services. It highlights the varied and differing manifestations of deafblindness, the effects it has throughout life and how the people affected by it attempt to live with it. However, the results also show that we have only been able to look at the tip of the iceberg. The consequences of age-related hearing and visual impairment and the interaction between sensory disabilities and other serious impairments, in the case of mentally disabled and mentally ill people, remain a grey area. Neither the SNAB nor other organisations are taking care of the thousands of people who can no longer hold a conversation in old age, who receive too little information and stimulation, who rarely leave their homes, who can no longer read and who are drifting into spatial and social isolation.

The study described here consists of 183 pages of information about deafblindness. The aim of this short summary in English is to present the most important results to interested experts and to a wider audience.

Can the projection of 213,900 people affected by this condition be correct? (Switzerland counts 7,870,000 inhabitants at the end of 2010). We have no reason for believing otherwise. However, we also know that when confronted by these figures we have no answers, even if we were to divide them by two, three, ten or one hundred.

The future will show which answers may be possible. In the meantime, we would like to invite you to read this summary of a study that does not attempt to understand deafblindness by measuring vision or residual hearing, but instead shows the people affected in the context of their lives and their experiences.

² Michel, K. (1984).

2. Understanding hearing and visual impairment

Judith Adler

In 2005 the World Health Organization (WHO) developed the International Classification of Functioning, Disability and Health (ICF). According to these criteria, a disability always results from the interaction of personal factors and environmental factors. As well as considering physical impairments, the ICF also focuses on how opportunities arise in the lives of disabled people to take part in everyday life and to play an active role in shaping it. Therefore, restricted functions are always dependent on context. This means that no direct conclusions can be drawn from the degree of a hearing and visual impairment about the situation of the person affected. Every case is different.

In an international context, a functional understanding of deafblindness is used. It relates primarily to the effects, difficulties and special needs which this impairment gives rise to. Deafblindness causes difficulties in learning, interacting and communicating and restricts the opportunities for participation and integration into society.

Deafblindness is a separate form of disability. It is not simply a case of adding together a hearing disability and a visual disability. Deafblindness manifests itself as a consequence of different combinations of hearing and visual situations. Therefore, for long years the terms deafblindness has only been used in the case of profound deafness combined with a complete loss of sight. The extent of the individual sensory impairments can vary! The functional understanding takes into consideration the fact that the consequences for people with a little hearing and/or sight may not be the same, but can be equally far-reaching as for people diagnosed with profound deafness and blindness. Why? When two senses are affected at the same time, it is not possible to use the other sense to compensate for the lack of the other.

As a result of these complex problems, people with deafblindness need specialist education, training and support facilities. Technical aids and rehabilitation measures designed for people with "only" a hearing impairment or with "only" a visual impairment can rarely be used successfully to help those with deafblindness.

The specific support required varies significantly depending on the age of the person, the time of life at which the condition developed and the type of impairment.

3. Objectives of the study and methods used

Judith Adler

The University of Applied Sciences of Special Needs Education (HfH) in Zurich investigated the living circumstances of people with a congenital or acquired deafblindness³ on behalf of and in collaboration with the Swiss National Association of and for the Blind (SNAB). The objective of the study was to produce a comprehensive description or reconstruction of the living circumstances, requirements and resources people living with deafblindness at different stages of life.

During a preliminary study, existing international research was analysed and summarised. A qualitative and quantitative approach was used to carry out empirical research into the living circumstances of people who are registered with the seven SNAB advice centres for deafblind people. People with an additional mental disability are also registered at these centres. These people were only included in the quantitative part of the investigation⁴.

The study was designed to answer the following questions: What are the living circumstances of people with deafblindness in Switzerland like, taking into consideration the relevant dimensions of their living circumstances and against the background of the living circumstances of the population as a whole and of people with disabilities? Which problems that face deafblind people in everyday life most urgently need to be resolved? Which resources can be used to help them?

The concept of living circumstances is ideal for a multidimensional evaluation of the situation in which deafblind people live. Social inequality is defined here as the result of relatively long-term living conditions and conditions for action brought about by society. While the objective conditions for actions describe the scope in both life and actions, the subjective side consists of the individual perception and use of the objectively available conditions for action. The conditions for action are broken down into dimensions⁵.

Qualitative interviews⁶ were held previous with 10 people to establish the relevant subjective dimensions of the living circumstances of hearing and visually impaired people. The interviewees were selected on the basis of the rules of theoretical sampling⁷, which involve identifying contrasting cases. After the 10 interviews, the subjects seemed to have been fully covered and the requirements of theoretical sampling had been met. The interviews were transcribed in full and evaluated using the Mayring⁸ qualitative content analysis. In addition, four interviews were held with experts to obtain valid data.

³ Adler et. al (2011).

⁴ To investigate these people with multiple disabilities, a different research approach would have been needed, which was not possible in the context of this project.

⁵ Gredig, D. et al. (2005).

⁶ Witzel, A. (1985).

⁷ Strauss, A. & Corbin, J. (1996).

⁸ Mayring, P. (1997).

For the main part of the study, a questionnaire survey and semi-structured interviews were used. A brief questionnaire about the socio-demographic data was completed for clients of the SNAB advice centres for deafblind people by the relevant social worker. It was possible to include in the analysis 338 of the questionnaires that were returned. A detailed semi-structured interview was held with 35 deafblind people from all the language regions of Switzerland. Four of these people had had deafblindness since birth. Four people from the 15-30-year-old age group were interviewed, 11 from the 40-55-year-old age group and 20 from the 75-90-year-old age group. All the interviews were transcribed in full and evaluated using the Mayring qualitative content analysis. This method was particularly suitable for these interviews as many of them were translated (between the Swiss national languages and with the help of sign language or the "Lorm alphabet" ⁹).

Although they were not asked about this, the interviewed people explained the large number of strategies that they use in everyday life, in social contacts and in dealing with their own disability. In order to evaluate the strategies and solutions referred, the concept from the research into ageing carried out by Baltes und Baltes¹⁰ was used, which allows for a resource-based analysis of the action strategies of the interviewees.

The research plans and questions were discussed with a group of deafblind people with the aim of developing a participative research strategy. Selected results and interpretations were also presented for discussion to the same group and two groups of interviewees one year later. A total of 11 deafblind people from German-speaking Switzerland and four from French-speaking Switzerland took part in these meetings.

⁹ The Lorm alphabet is a form of communication between deafblind people and other people. The person "speaking" touches the palm of the person "reading". Letters are assigned to individual fingers and different parts of the hand.

¹⁰ Baltes, P. & Baltes, M. (1989).

4. Study results (Summary)

Judith Adler, Corinne Wohlgensinger

4.1. How many people are affected?

A number of studies have been carried out and estimates made of the frequency of deafblindness in European countries. On this basis the estimates of the number deafblind people in Switzerland are as follows:

- A total of 214 people born in situation of deafblindness.
- Between 285 and 428 people with Usher syndrome¹¹.
- Between 8913 and 213,900 hearing and visually impaired people aged over 65 who developed the disability in old age.

People can also develop deafblindness in adulthood, but there are no estimates of the size of this group. It is also important to take into consideration the growing group of premature children with severe multiple disabilities whose additional sensory impairments are not always diagnosed.

As a result of demographic changes, the number of people over the age of 70 will continue to increase and, therefore, also the proportion of people with an age-related, acquired deafblindness.

Of the 338 clients of the SNAB advice centres, 59 or 17.5% have an additional mental disability. The living circumstances of these persons are very different from those of the other clients. This group has therefore been evaluated and described separately. In the following sections, the deafblind people without a mental disability are described first.

Most of these people are of retirement age and many of them are in adulthood. The age distribution shows that a part of children and younger people are probably supported by other advisory bodies. More women than men seek the help of the advice centres, which is partly a result of the longer life expectancy of women.

The questionnaire asked about the current status of the disability. Only a highly simplified categorisation of the impairments was possible¹². The smallest group consists of people who are both deaf and blind. Almost two thirds of the people affected have a small hearing and visual potentiality. A quarter of the people surveyed have Usher syndrome.

Many people had a hearing loss from the early years of life and another large group acquired it in middle age between the ages of 40 and 65. The early occurrence is important because it makes the acquisition of spoken language much more difficult. A large number of people also developed a visual impairment at a very early age. The age at which the remaining people acquired the impairment is evenly distributed

¹¹ People with Usher syndrome are born deaf or with a hearing impairment and become blind or visually impaired.

¹² A rough distinction has been made between hearing-loss and deaf and between blind and visually loss.

across the other age groups.

The way in which the interviewees described their hearing and visual impairment in the interviews shows that there is no single impairment. The difficulties with seeing and hearing, the time at which the impairment began and the progression of the condition differs significantly. The condition can be progressive or remain stable. It can also change quickly or slowly. The degree of the impairment may also fluctuate. The combination of all these factors results in very different living circumstances. One factor which all of the people have in common is the restrictions placed on their lives by the impairment of two distance senses.

Many of the interviewees suffered high levels of mental stress as a result of their disability. One possible way of dealing with this is to accept the disability, to look at the positive aspects of it, to hope and to believe that it will not deteriorate and to adapt constantly to the new situation. People who developed the disability in old age in particular try to take a positive view of their life as whole. However, some people talk about becoming resigned to their situation.

One woman explains her state of mind when she lost the sight in one eye¹³:
"I already felt stressed. I was already mentally... I almost ... felt as if the roof was falling on my head. Mhm. Eh, but I could still, eh ... I could still cope with it. But not ... I could make the best of it. I tried to feel happy about other things. But it really did make me sad... Then I had other medical problems, how can I explain it? Eh, it simply all became much too much for me." (33, 41-52)

There are three problem areas concerning the health of the interviewees. These are age-related, disability-related and other illnesses or health problems. Disability-related health problems are, for example, the result of falls and accidents caused by the deafblindness.

4.2. Education and employment

A large proportion of the SNAB clients attended a special school, in particular those people who have had a hearing impairment or a hearing and visual impairment since the early years of their life. The highest professional qualification among the majority of the interviewees is a professional or vocational apprenticeship. People who have been deafblind from an early age are much less likely to have completed a professional or vocational apprenticeship. A comparison between the educational details of all the deafblind people (including those with a mental disability) and the educational details of disabled people in Switzerland¹⁴ shows that on average a lower proportion of the deafblind people have completed vocational training and a higher proportion have a compulsory school-leaving qualification. The proportion of people who have completed basic vocational courses is similarly high.

More than half of the clients of the SNAB who do not have a mental disability are over the age of 65 and are retired. Of the people interviewed who are of working age,

¹³ Some excerpts from the interviews have been included to illustrate the results.

¹⁴ Cf. Gredig et al., 2005.

38% are working, but around one third of them work in a sheltered workplace or workshop and the majority work part-time.

In comparison with other disabled people in Switzerland and with the population as a whole, deafblind people are much less likely to be employed and much less likely to work full-time. They are at a serious disadvantage in terms of both education and employment.

However, the interviews made it very clear that work is of great importance to the young and middle-aged deafblind people. A job has a major influence on their financial situation, social contacts and leisure activities. The lack of employment has a direct impact on their mental well-being, because it gives them the feeling that they are not able to do anything useful and that they are not needed.

As only very few of the hearing and visually impaired people are working, the focus is on issues such as unemployment, the amount of things available to do, pressure to be active and ways of spending time. Filling their free time is a challenge for many of the people. Depending on their interests and the opportunities available, they take up a wide variety of activities. The majority of these are creative and sporting pursuits. The ability to take part in voluntary work, adult education classes or club activities can be restricted by their disability.

4.3 Finding a job and keeping it

For deafblind people, there are three main problems with regard to work. The first, which affects the young in particular, is getting a foot on the employment ladder or, as a preliminary to this, gaining access to training. They encounter a great deal of prejudice and uncertainty from employers. Nevertheless, many of them are untiring in their commitment to entering the world of work. It was clear that when the training establishment put more effort, time and energy into the process and was prepared to make adaptations, it was possible for deafblind people to acquire a qualification.

The second problem is keeping a job. Many of the interviewees are confronted by difficulties in the workplace caused by the progression of their disability, combined with a lack of adaptations in the workplace, which is also related to a lack of commitment on the part of the employer. For many people the challenge lies in keeping their job despite these setbacks. However, they often do not succeed and ultimately become unemployed. People with deafblindness also have to give up their training courses in cases where not enough adaptations are made to accommodate disabled people.

“Within a relatively short time my hearing loss became much worse. About five years ago, I got my first hearing aids. Before that I always had to ask two or three times before I understood and above all I had real difficulty understanding some people at all. At that time I worked at x and after that it was really no longer possible. In all the hustle and bustle I had trouble hearing anything.” (45, 5)

The third problem area relates precisely to this loss of work, which hits many people very hard. Not being able to do a useful and productive job any more, combined with the lack of social contacts in the workplace, represents a major problem for many

people. One factor which makes this even more difficult is the fact that deafblind people often have the impression that they can still work, but that they have no opportunity to do so.

"I wasn't able to because of my hearing and visual impairment and it really is a disaster when you're excluded from the world of work, isn't it? It's not good. For example, I'm currently learning something new. I'm doing something, but it's for me... really I'd like to do something for other people as well. Then I'd feel better. But like this we feel as if we're excluded from real life. It's not good." (12, 375)

4.4 Different housing situations

Almost one third of the interviewed people live alone in their own home. The majority live with a partner or relative and around one fifth live in a home for disabled or elderly people. People who are blind and deaf and those who have had a hearing and visual impairment since birth are more likely to live in an institution. In the interviews it became clear that contact with neighbours, having shops and footpaths nearby and being able to be independent were very important to the interviewees.

"I'm happy living here on my own. Of course, I'd like to be married, but living with someone else would be difficult at my age and with a disability. Living alone means that I am free." (25, 43-44)

4.5 Saving and economising are important subjects

All person with deafblindness over 65 years old receive a retirement pension. Around four fifths of the people of working age (18 to 65 years old) receive invalidity benefit. Overall, deafblind people claim supplementary benefits to their invalidity benefit or retirement pension much more often than the average in Switzerland as a whole. This indicates that many deafblind people are in a difficult financial situation, which is due, among other things, to the low employment rate. The financial burden seems to be even greater for people who live alone and cannot share their living costs with relatives. In comparison with other disabled people in Switzerland, an above average number of deafblind people are entitled to claim severe disability benefit. Fewer are entitled to moderate disability benefit. The interviews also make it clear that saving and economising are two important subjects. The interviewees also talk about the lack of money to pay for aids and helpers. This may be due to the way in which disability benefit is calculated, as it is based primarily on day-to-day tasks.

"It's enough for me, because I don't have many outgoings. Also I spend most of my time at home, so it's OK, it's not too bad." (12, 221-232)

4.6 There is no single "deafblind language"

The communication options available to deafblind people vary significantly. In the right environmental conditions, they can often still make use of their sight and / or hearing. They use a wide variety of different forms of communication and combine

them, in order to continue being able to take part in conversations. The most common forms are normal speech and (enlarged) normal print¹⁵. There is no single predominant form of communication, such as a "deafblind language". All the available forms and means of communication are used.

The interviews also make it clear that communication is central to the participation of people in society. It is closely related to social contacts and work. One major problem is the difficulty or sometimes the impossibility of taking part in conversations in groups, which is also caused by the way in which other people communicate. The second problem area is background noise, which makes it impossible to hold a conversation in noisy places, at events or in places where large numbers of people meet.

The progression of the impairment, which is often gradual, is the third problem area in communication. The forms of communication which the deafblind person has learned may become unsuitable. The fourth problem emerges in particular in communication with unknown people and that is the ignorance and, therefore, the uncertainty of other people about direct conversations with deafblind people.

The interviewed people use a variety of strategies to allow them to take part in conversations. They arrange conversations with just one other person in a quiet setting. They ask the other person to keep to the rules which will enable them to understand and they ask for more time to understand. They make a greater effort and concentrate more in order to comprehend what is being said. Sometimes they simply pretend that they have understood. Other possibilities include restricting contact to people who can use the necessary forms of communication or not taking part in group conversations. They also choose other strategies, such as using all the available forms of communication and learning new means of communication. In addition, they use technical aids for hearing and visual impairments and, if this is not enough, they have to organise third parties (sign language interpreters, SNAB communication assistants or SNAB volunteers trained in communication methods). Depending on the type of communication, these people interpret into sign language, communicate by means of the Lorm alphabet, repeat what is being said with clear lip movements or summarise the conversation in spoken or written form. Younger people also use modern means of communication such as e-mails and text messages¹⁶.

"Yesterday I was invited round by a family, they invited me to visit... We hadn't been in touch for a long time and they invited me yesterday. A few other people came, so there were 12 adults and two children. I was sitting there and the noise level was so high and I prefer talking one-to-one, the sort of conversation you have when you meet people. That's easier for me than a big group, that's... They wanted me to stay for the afternoon, but I knew that I'd had enough." (46, 105)

"I feel most comfortable in a normal environment where it's a bit calmer. I don't go out much at weekends, because it's usually too loud for me. What are the options? I can't go to discos or things like that, because there's too much noise, or pub crawls, because there are too many people all talking at once. How can I explain it? In groups

¹⁵ For information on the forms of communication for and with deafblind people, see the SNAB brochure "Grüezi, ich heisse ..." (Hello, my name is...). Available from: www.szb.ch

¹⁶ Cf. footnote 17.

where there are more than three or four people it's sometimes difficult because I'm trying to have a conversation with one person and there are two others going on next to me... you really want to listen to everything that's happening." (35, 33)

4.7 Independent mobility means taking risks

For the people interviewed, being independently mobile, for example, being able to go out on their own, is very important. However, there are also problems which are connected to the difficulty in finding their way about, including using public transport, crossing busy roads, places where there are a lot of people and the risks and dangers facing deafblind people when they go out on their own despite their restrictions.

In this area, deafblind people also develop strategies. They allow more time to get to their destination, they practise familiar routes (as part of mobility training), they make detailed preparations for a journey, they organise someone to accompany them and they use aids. In order to maintain their independence, many of the interviewees go out on their own, which means that to a certain extent they are at risk of an incident or accident occurring. If they cannot organise anyone to go with them or if they feel too uncertain, the result is that they stay at home.

"Well, the route to work or the routes that I use regularly... they are... I've worked them out and I can manage on my own. That means I can simply decide to go out then and there." (23, 142)

Another person on the subject of crossing the road:

"With the hearing impairment it makes it relatively difficult for me, mainly with everyday things, when you're in a room with lots of people or, for example, you're out on the street and you want to cross the road and there's a lot of background noise or something, then sometimes I pray to our saviour to get me safely across the road, I really do ... (laughs), I hold my stick out and I hope that a car stops. That's what it's like." (45, 5)

4.8 Acquiring information means belonging

For deafblind people access to information means being involved and being able to join in the discussion and not having the feeling that has been described of "coming from another planet". The main problem areas are as follows: access to information about current affairs, information in a learning environment, information needed to cope with everyday life and information about social events in their own personal circle and about public cultural events. In this area the interviewed people also use a variety of strategies. They choose the most suitable medium and select short extracts containing the information which is most important to them. They allow themselves more time. Aids and personal support are important factors in enabling them to access information.

One person mentions that she is not informed about events:

"... well, the (old people's home)¹⁷ sometimes stages shows or invites someone to come and entertain the residents, but I generally don't know about it. They put it on the noticeboard downstairs, there's a poster, but I can't read it at all. And if I don't ask someone to read out all this stuff to me, then..." (22, 411-413)

4.9 Social contacts, dependency and loneliness

Social contacts and the feeling of inclusion are closely connected with other areas of life, in particular with the possibilities for communication and mobility. It is clear that the question of whether and to what extent someone is able to make and maintain social contacts depends on a large number of factors. To visit friends, do things with others or get to know new people, it has to be possible to go out on foot or use public transport, buildings have to be accessible and the environmental conditions must be right. Social contacts are also a source of emotional and practical support.

One major problem area is dependency within relationships, because deafblind people often rely on help, sometimes for highly personal matters. The subject of dependency and independence has already been referred to in the context of mobility and day-to-day tasks. However, in the case of social relationships it plays a central role.

One strategy relating to dependency on others in social contacts is to offer the helper a service in return. The assistance budget¹⁸ is also seen as a means of abandoning the role of recipient of help. Another strategy is to do as much as possible independently, but to be aware of one's own limits and not to go beyond them.

"Yes, I do need help. But I can organise the help myself and decide what will happen when and how. I should perhaps say in this context that I'm taking part in the assistance budget pilot project (...) and I told them that I'm happy to accept this help on condition that I pay for it. At first everyone was surprised, but then they agreed. But it's easy, it's really nice (laughs)... it's all about self-determination. It makes it easier for me to ask people, otherwise I feel as if I'm asking for charity..." (23, 37)

4.10 The threat and the experience of isolation

A very serious problem for deafblind people is their experience of loneliness and social withdrawal. In order to combat loneliness, people increase their contacts with their family and neighbours or move to be near their family or to an old people's home. One way of dealing with this problem is also to find distractions, keep busy doing other things or to stay in touch with people via the Internet.

Deafblindness has a direct impact on another problem area: Making contact with new people and maintaining friendships is very difficult. How can deafblind people meet new people, get into conversation with them and develop a serious relationship? The interviewees rely on contacts with people they know. They maintain old friendships and contacts with family members or look for people to meet at events for deafblind

¹⁷ Author's note.

¹⁸ As part of the assistance budget pilot project.

people or for hearing-impaired and visually impaired people. Another option is to take a helper with them to make communication easier.

Another problem with making contacts is the lack of understanding of this type of disability among able-bodied people and, therefore, their uncertainty, their lack of commitment and their rejection of contacts with deafblind people. These experiences give the disabled people the feeling that with their dual sensory impairment they should not be imposing themselves on other people. In order to overcome this difficulty, they need to describe their disability and explain to the other person how to communicate with them.

"I think it's really the hearing loss, because if you're blind you can still manage. People can understand that, it's still possible to communicate, but if I have to ask three times before I understand, it's just too difficult for other people to grasp." (1,112)

4.11 Challenges with leisure activities

As already mentioned, it is a particular challenge for deafblind people to keep busy and to fill their days without having a job. This is especially a problem for the unemployed people, but also for the older interviewees. Some of the people surveyed find alternative occupations (such as voluntary work and creative activities). However, it is often not possible to take up voluntary work. Adult education classes which are not aimed specifically at hearing and visually impaired people are in many cases not accessible. This leaves only activities intended for deafblind people or a creative activity at home. This last option leads to increased isolation.

"Just the fact that I have something to occupy me is very important to me. Money doesn't really matter. Of course, I could use some money... but being busy is what's important. Otherwise, I would give up and just sleep all the time, which isn't good. My goal is to find an occupation which I can do despite the fact that I'm blind. At the moment, that's SNAB's workshops in Lenzburg. There, at least, I have a person sitting next to me." (17,438)

The interviewees have a wide range of leisure activities and occupations which change over time and as their disability progresses. Everyday tasks (housework, shopping, correspondence and paying bills) are difficult for many people with deafblindness and in many cases they need to spend more time on them. Nevertheless, many of the interviewees are able to do a lot of things themselves, which is very important to them. Independence becomes even more important as people get older. In particular, they want to hold on to their independence for as long as possible, because it is also being threatened by age-related health problems. As someone's independence diminishes, they have to build up a support network of private and professional helpers.

5. Hearing and visually impaired people with a mental disability

Judith Adler, Corinne Wohlgensinger

During the course of the study it became clear that the living circumstances of the deafblind people with a mental disability were very different from those of the other clients of the SNAB. However, important information emerged from the analysis of the questionnaires of the 59 mentally disabled people who are registered with the seven SNAB advice centres. These people are on average much younger than the other clients. Most of them are between 30 and 59 years old. The majority of them have had severe multiple disabilities since birth and generally they had a hearing impairment and a visual impairment before the age of 1. The fact that mainly younger people are registered with the SNAB advice centres could be because it is difficult to diagnose a visual impairment in mentally disabled adults or because the impairment is disregarded. A study carried out by the HfH shows that severely mentally disabled people and mentally disabled adults are particularly at risk of not having an adequate diagnosis and not receiving appropriate care for their visual impairment¹⁹.

Mentally disabled people are much more likely to live in an institution for disabled people and to have a lower level of education than other deafblind people. The majority of mentally disabled people with a hearing and visual impairment have an occupation in a remedial education institution. Only a few of them have a job. Almost all deafblind people with a mental disability claim supplementary benefits and all of them claim disability benefit, most of them for a severe degree of disability. In the case of these people, the disability benefit is not linked to the combination of a hearing and visual impairment, but to the extent of the mental disability and other disabilities. In addition, mentally disabled people use fewer forms of communication than people with acquired deafblindness and are most likely to opt for simple signs and pictograms (pictures or objects with a meaning).

¹⁹ Adler, J. et al. (2005).

6. Subjects relating to overall living circumstances

Judith Adler, Corinne Wohlgensinger

The extent, the start and the progression of the sensory impairments differ significantly among the people who took part in the study. Nevertheless it is possible to identify common problems, solutions and coping strategies. During the subjective evaluation, overall themes repeatedly emerged which, of course, were given a different emphasis depending on the person and their situation.

The progression of the disability

One particular challenge is the progression of hearing loss and visual loss. The study highlights the fact that people have to be very flexible in constantly finding new ways and means of accessing information. They have to learn new forms of communication, in order to continue taking part in conversations. When deafblind people of working age lose their job because their hearing and / or sight are deteriorating, they often make fruitless attempts to take up other activities (voluntary work or other occupations). Coping in emotional terms with this progressive disability is a major challenge.

Dependency on personal helpers

When the aids for deafblind people no longer do the job or can no longer be used, a personal helper is needed. The dependency on being accompanied becomes an important issue in many areas, for example in communication, social contacts, access to information, mobility, work and training and in relation to the financial situation of the disabled person.

When people need a personal helper, they often fall back on a network of family members, friends and acquaintances. If this support network is missing, they have to pay for help or rely on volunteers from institutions. If the disabled people are in a poor financial situation, this can become a problem.

Personal resources

Many of the interviewees explain that they have a lot of independence in many areas, which is made possible by using different strategies. These are their personal resources. Often the strategies involve spending more time and energy or making careful preparations, for example. During conversations, contacts and the process of finding their way around, more concentration is needed to take part in activities using the available visual and auditory information. This results in the hearing and visually impaired people often only being able to take part for a limited time. Another central strategy involves reformulating goals and this includes giving up previous goals. This strategy is particularly apparent in areas such as social contacts and communications.

Experiences of discrimination and isolation

Deafblind people very often experience discrimination. Their options for participating in society are heavily restricted. This becomes obvious in areas such as social contacts, communication, mobility, access to information, work and their financial situation. There is a serious risk of becoming isolated. It is difficult for people to make and maintain social contacts as their options for communicating diminish. The evaluation

of the quantitative data shows that deafblind people are at a significant disadvantage when it comes to taking part in working life and in higher education. In addition, the financial situation of the clients of the SNAB advice centres is worse than that of other disabled people, which makes participating in society more difficult.

Hearing and visual impairment on the CV

The study involved an investigation of the living circumstances of deafblind people in three age groups: young adults (15 to 30 years old), middle-aged people (40 to 55 years old) and elderly people (75 to 90 years old). The greatest difference between the three age groups is in the field of work. The young people put all their energy into education, training and looking for a job. The middle-aged people are in the most difficult situation in this respect. The loss of a job and exclusion from the world of work are key issues which cause a great deal of stress. The support provided to this age group must focus on retaining existing jobs or identifying other productive activities. The most important consideration for the elderly people is health problems. The rehabilitation of older impaired people must concentrate on maintaining their independence and their ability to do everyday tasks.

7. Challenges and future prospects

Stefan Spring

Previous projections led the SNAB to assume that there were between 1300 and 2000 people in Switzerland suffering from deafblindness. This study, which is the first comprehensive investigation of its kind in Switzerland, is based on more recent statistics from different European countries. It shows that hearing and visual impairment is much more common than previously assumed. In particular, the estimate of the number of elderly deafblind people has risen significantly. The more cautious estimate gives the figure as 9000, while the more generous estimate exceeds 200,000 people. The SNAB will base its work on the conservative estimate and will now assume that there are at least 10,000 people in Switzerland who are affected in different ways by deafblindness. What impact do these new findings have?

We should not assume that all the people affected will turn to a specialist SNAB advice centre. Advice is always made available on voluntary basis. The involvement of a self-help organisation is not necessary in every case and is also not suitable for everyone. What we as an umbrella organisation should be concerned about is the fact that many people are living with the consequences of their disability, as described in the study, without receiving adequate support. If the specific consequences of a dual sensory impairment are not identified, the quality of life of the people with the condition and of those around them will be significantly reduced, because deafblindness affects not only one individual. It is a classic social and communication-related disability. The close relatives and friends of the person are also seriously affected as a result of misunderstandings in communication, the time and effort spent conveying information and the support provided when accompanying the disabled person. The deafblindness of one person has an impact on a whole group of people.

The funding which the SNAB receives from the Swiss Federal Social Insurance Office and from its many donors is only just enough to provide advice and support to around 400 people. The advice service cannot be extended to cover 1000 people and certainly not 5000 or 10,000. It is difficult to find new and generous donors and our public funding will not be increased under the current circumstances.

Another important insight is that sensory impairments are widespread among elderly people and that the combination of two sensory impairments is far more common than previously thought. Given the projection of 213,900 people with the condition, we must work on the basis that two out of ten elderly people will be affected by a hearing and visual impairment to a greater or lesser degree. In these categories, the previous view of disability as an exception is no longer appropriate. Hearing and visual impairment is a widespread phenomenon in old age. We must no longer focus solely on the strategy of improving the living circumstances of deafblind people by means of the services provided by the advice centres.

Changes are also needed in the disability system. Our structures and concepts still focus far too heavily on identifying and supporting people who have been disabled from birth or who become disabled during their working life. However, anyone who

has had satisfactory sight and hearing throughout the major part of their life will hardly start regarding themselves as disabled at the age of 70, 80 or 90 and decide to attend an advice centre. Deafblindness must therefore be understood as a widespread experience of a life with restricted hearing and sight.

Therefore, the study leads to a new approach. Instead of considering disability to be a special case, it will now be seen as a common experience of reduced sensory perception in old age, at a time when more and more people are living longer. The challenges involved go even further. Changes need to be made to buildings, to the organisation of services in the public and private sector and to the design and the efficiency of everyday objects. In addition, the general public must be made more aware of the problems encountered by people with a hearing and visual loss.

Communication and access to information are important features of the rehabilitation aimed at deafblind people today. However, the subtle effects of a wide-ranging dependency on relatives, friends, specialists and companions are something which the advice service takes into consideration. Deafblind people can achieve and experience very little without relying on favours or payment. It is very stressful for them to have to depend on the people around them having the time and the inclination to help them. Many personal relationships become based on one-sided taking and anyone who pays for a helper, for example using the personal assistance component of invalidity benefit, will rapidly come up against the limits of the Swiss social insurance system.

The SNAB is prepared to face up to all these challenges, but it relies on partners to be able to do this. These are people who are in contact with elderly people, who advise, support and care for them. They are partners who advise people with hearing or visual impairments, who diagnose their medical conditions and provide them with visual or auditory support. They are also partners who are aware of the hidden consequences of sensory impairments for people who cannot read, drive a car or take part in complex discussions.

8. A more detailed description of some of the people involved in the survey

The following brief examples give an insight into how the interviews were run and into the different living circumstances of the interviewees. We have selected cases which differ from one another as much as possible, with regard both to the survey method and to the living circumstances.

Mr A

Mr A has had a hearing loss and a visual loss since birth. He says that he is very short-sighted and sensitive to light and that his hearing fluctuates. At the time of the interview he was in his mid forties. The interview was carried out in normal speech. An interpreter for the interviewee's native language was present, together with an employee from the institution at the interviewee's request. After every question Mr A looked for a long time at the employee from the institution before he answered. Following the question about his job, he asked the employee if what he did was a job. His answers were very short. During the week, Mr A lives in his own studio flat in an institution for disabled people. He said that he is happy living there because he feels protected to a certain extent and because everything is adapted to his disability. He always has someone he can contact if he has questions or problems. He cooks his evening meal himself in his small flat. He works full-time in the facilities management team of the institution. He enjoys the work because the team is small, the manager supports him and adapted aids are available. He is in contact with individual friends inside and outside the institution. He has most contact with his family and he travels on his own by train to visit them every weekend. He uses a white cane when he travels. In his spare time he goes out with other residents of the institution, writes e-mails, chats and surfs on the Internet using speech output software and listens to audio books.

Ms B

Ms B is in her mid seventies and has been almost completely deaf since birth. She has had very poor sight for the last 15 years and can no longer lip read. The interview was carried out with a SNAB communication assistant. The questions were spelled out to Ms B using the Lorm alphabet and she answered in normal speech. This was repeated by the communication assistant to make it more comprehensible. The questions had to be phrased simply and sometimes repeated. Her answers were rather short. The interview had to be kept brief, because using the Lorm alphabet is very tiring. Ms B lives alone in a small flat and looks after herself and her home, with the exception of cleaning. She is now retired but still pursues a number of creative activities. She goes out alone and goes shopping, but only with a notebook and a thick felt pen. She uses these to get help from passers-by if necessary. She only has contact with people who can use the Lorm alphabet.

Ms C

Ms C is in her mid forties. She has had a hearing impairment since birth and became visually impaired as an adult. The interview was carried out in normal speech in her flat, where she lives alone. She goes out with a white cane and uses public transport in her area. She does the housework and correspondence etc. herself. Until a few years

ago she had a job. She used a number of aids in her workplace, but as her sight deteriorated, she was no longer able to do her job. For a while she thought she could still work, but now she can no longer imagine working. After giving up her job, she took adult education classes to train as a volunteer in social institutions. However, she was not able to get any voluntary work. Ms C explains that the people asked by the organisation were uncertain about her because of her hearing and visual impairment and, therefore, she was not given any work. She attempted to take a course not designed for disabled people in a craft technique with a SNAB volunteer, but she had to give up because her impairments meant that she could not follow the course in the group. Today Ms C keeps busy with creative activities at home. She has few social contacts.

Ms E

Ms E is 40 years old and lives with her family. She has been deaf since birth and her sight deteriorated in her teens. At that time she was diagnosed with Usher syndrome. This means that her sight will deteriorate further. The interview was carried out with a sign language interpreter who translated the questions. Ms E answered in spoken language. If the interviewer did not understand something, the interpreter repeated it in spoken language. Ms E can still read large letters on the computer and goes to familiar places on her own. She has already learned Braille and reads Braille books for practice. Ms E can write with the Lorm alphabet. She says herself that she will learn to read the Lorm alphabet when she needs to. Ms E works part-time in adult education. She takes a sign language interpreter with her to meetings at work. She has hearing and deaf friends, but she feels most at home in a group of deaf people.

Mr D

Mr D has been living for three years in an elderly people's home after undergoing an operation. He is in his late eighties and lost the sight in one eye 15 years ago. Shortly afterwards he suddenly lost the hearing in one ear. Following an illness a few years ago he can now see very little with his other eye. A year ago Mr D suddenly lost the hearing in his other ear, but now he is slowly starting to hear a little again. The interview was held with a relative, as an interview with Mr D was not possible. Mr D understands hardly anyone any more. After losing the hearing in his second ear, he became very depressed. The only means of communication with him is to write essentials in large letters on an A4 sheet. At the moment he can understand some of what his relative says if she uses short, clearly worded sentences. Mr D still has a very good memory, which helps him to make use of the brief information he is given. Sometimes he goes for a short walk with a helper, otherwise he mostly just sits in his chair. He cannot hold conversations any more in the real sense of the word. His contacts in the old people's home are restricted to nodding to an old acquaintance who also lives there.

9. Literature

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Who we are

The Swiss National Association of and for the Blind (SNAB) was established in 1903. Its main office and secretariat is located in St. Gallen. It endeavors to give partially sighted, blind and deafblind people the opportunity to determine their own way of life.

The SNAB is the national umbrella organization for 60 member organizations, which are all active in the field of blindness. As such, the SNAB coordinates all efforts on behalf of and for individuals affected by sight loss, promotes contacts and spreads information. The SNAB provides information and direct aid to partially sighted, blind and/or deafblind people as well as to its member organizations, public and private institutions and to concerned members of the general public.

SNAB provides 7 Advice Centers for deafblind people all around Switzerland (Bellinzona, Berne, Lausanne, Lenzburg, Lucerne , St. Gallen, Zurich)

General contacts: Central office: sekretariat@szb.ch. Office Lausanne: sekretariat@ucba.ch

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