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The Eikholt model

Our theoretical and ideological point of view

Ann-Britt Johansson and Rolf Lund

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The Eikholt model. Our theoretical and ideological point of view

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Ann-Britt Johansson and Rolf Lund

PREFACE

We would like to point out that this report is a product of an internal process where the management of Eikholt wanted a document that describes our practice and what this practice is based on. The process has consisted of a survey among people with acquired and congenital combined visual and hearing impairment/deafblindness and their families (henceforth referred to as users) who have participated in our rehabilitation courses that gave us insight into their value at Eikholt and what we should strive for (Eikholt, 2020a). We also spent a number of days on group work where the employees at Eikholt described what they experience as positive and what they think the users value. In this process, we tried to look ahead and describe where we want the development to continue. There was great agreement that we must take care of the best in current practice and further develop in all other areas.

In the work of writing down what emerged in the user survey and in the internal processes, we have received good input from Roar Meland, director at Eikholt and our department manager Thomas Øverby. In addition, Alf Reiar Berge has been a good mentor. He has both long and deep experience with the topic. Through Rehab Nor, he has had many assignments for the Norwegian Directorate of Health and Norwegian municipalities in projects with special emphasis on ideology and principles in the work of rehabilitating people with disabilities.

This report is intended as a documentation of Eikholt's theoretical and ideological point of view. By theoretical point of view, we mean a description of our professional point of view, current concepts and the connection between them. How this is done in practice is described in what we have called a user journey. Eikholt's ideological point of view is a description of our system of ideas, basic views and views on society. An ideology is largely governed by which interests dominate. For Eikholt, this is largely characterized by how we came to be, as a response to user needs and that the development up to today has largely been user-driven.

It is important to read this report as an expression of what we are, but also of what we want to be. The Eikholt model will influence the work of achieving the goals for the business.

In connection with this academic report, a short version has been prepared that can be used in connection with presentations of Eikholt.

Eikholt, 10. september 2022

Contents

Eikholt - a resource center for opportunities and development

Since 1980, Eikholt has offered services to people with acquired and congenital combined visual and hearing impairment/deafblindness, their families and professionals in the local health care.

The UN Convention on the Rights of Persons with Disabilities states that universal human rights apply in full to all. One of the goals of the convention is that people with disabilities should have an independent life and be able to participate fully in all areas of life (UN, 2022)

The government, in collaboration with organizations for the disabled, has prepared the document «A society for all. The Government's strategy for gender equality for people with disabilities» (Barne- og likestillingsdepartementet, 2018). The effort rests on the following four pillars:

1. Develop both universal solutions and special measures.
2. Work for self-determination, participation, and inclusion.
3. Better coordination at all levels.
4. Four focus areas; education, work, health, and care, as well as culture and leisure (Chapter 4).

Eikholt's history as a basis for our point of view

Eikholt's origin and history is something we are proud of and take care of. Mason Olaf Frøiland was a skilled craftsman with his own company, in addition he was exceptionally socially engaged. This commitment brought him into contact with Halvdan Larsen, who had deafblindness. With his ability to empathize, Olaf Frøiland quickly saw that what Halvdan Larsen and others with deafblindness needed was a gathering place. Frøiland owned a large area on Drammen which he was willing to use for this. He and Larsen traveled around the country and to inspire and raise money.

Eikholt's ideological point of view is a description of our system of ideas, basic views and views on society. An ideology is largely governed by which interests dominate. For Eikholt, this is largely characterized by how we came to be, as a response to user needs and that the development up to today has largely been user-driven.

In the late 1970s came the plans, the drawings and finally the shovel could be put to the ground to build Norway's first and only nationwide center for people with deafblindness. Eikholt National Resource Center for the Deafblind was completed in 1980 and was opened on 26 August the same year by King Olav V. When Eikholt became a reality, it was not long before the users of the center noticed that recreation is good, but that they also missed activities. Based on these reactions, extensive course activities and knowledge production have emerged at Eikholt. These have always been developed in close contact with the users of the place. No one is better able to say what people with deafblindness need than those who themselves live with this disability (Eikholt, 2020b).

Today, the course business spans a wide range of opportunities. New services are constantly emerging and some fall away, depending on developments elsewhere in society and what the target group demands. Eikholt has undergone a fantastic development and today stands out as a unique center with user services within mapping and optimization of vision and hearing function, competence development, research and competence dissemination. Eikholt have retained its function as a meeting place for users from all over the country (Eikholt, 2020b).

Foundation

Eikholt is organized as a non-profit foundation with a short distance between users, professionals, and management. This makes the center dynamic, independent and innovative. It is easy to take new steps in the development of the center. We want to play an active role in the realization of the government's strategy for people with combined visual and hearing impairment/deafblindness to have the same opportunity to participate as everyone else in our society. This requires us to be constantly on the lookout for new knowledge that makes our services better. Eikholt actively contributes to research and innovation in the field that is disseminated both nationally and internationally. New knowledge and competence are developed based on the significant clinical activities that are conducted. It is a short way from research to the use of new knowledge in the service to users and their families.

Deafblindness can be a progressive disability

Combined visual and hearing impairment leads to extensive challenges in relation to information, communication, and mobility with the outside world. Many of those who need services from Eikholt have progressive sensory loss that has consequences in everyday life. This means that learned strategies and aids must constantly be changed and renewed, which entails a need for lifelong learning (Johansson, 2017). Sensory loss that progresses and lack of adequate relevant measures can lead to significant mental tension and stress, which must be captured and emphasized in the rehabilitation work. Consequences such as poor mental health and the feeling of being isolated are not uncommon (Johansson, 2017, Ehn, Möller, Danermark., & Möller, 2016). This can lead to treatment-requiring medical and social

problems that come in addition to sensory loss. It is important that personnel in the health service are observant in relation to such problems and implement necessary measures. Eikholt sees it as a main task to equip users, their families, and their support system to master everyday challenges that are caused in the absence of a world designed in a way that addresses their needs similar to the way other people's needs are catered for.

National responsibility for adaptation courses

Eikholt has a national responsibility for the NAV (The Norwegian Labour and Welfare Administration) adaptation course for people with congenital and acquired combined visual and hearing impairment/deafblindness. Adaptation courses are a right under the National Insurance Act (NAV, 2020) which also includes close persons. The purpose of the courses is to strengthen the individual's ability to cope in daily life, school/education and in working life.

National Resource Center

Eikholt is a nationwide resource center in the specialist health service and is part of a unit in the National Advisory Unit on Deafblindness (NKDB). Eikholt have build up and spread expertise on combined visual and hearing impairment/deafblindness (Eikholt, 2020b). It is crucial that professional environments that meet people with a hearing or vision problem are aware of the possibility that there may be a double sensory impairment that must be followed up.

We focus on information and competence dissemination both at the individual level and at the system level in various parts of the service apparatus. At the individual level, the needs are clarified with the individual in each case. There may be counseling/guidance for the person's close network, courses, subject days and teaching for kindergartens/schools, workplaces, the primary health service or other parts of the specialist health service, NAV etc. In such cases, we cooperate to a large extent with the regional centers in NKDB.

There is currently a restriction that Eikholt cannot offer its services to people who experience a combined sensory loss due to age-related sensory impairment. We know that this group is large, very large. Regardless of this limitation, we spread knowledge about combined sensory loss through lectures at universities and colleges, within various subject networks and in relevant academic environments, as well as at national and international conferences.

National meeting place

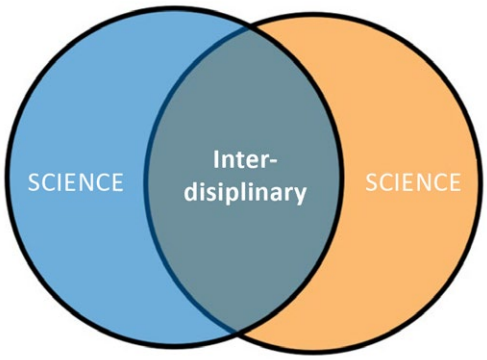
We place great emphasis on creating a vibrant arena for everyone who uses Eikholt. Many express that they benefit greatly from meeting others in a similar situation. Exchanging experiences and socializing with others with user experience has a value in itself. We also see that people who are in different phases of life and with different experiences related to the double sensory impairment, benefit and enjoy meeting each other. A service at Eikholt provides opportunities for meaning, community, development, and increased quality of life.

Multidisciplinary or interdisciplinary, specialist or generalist

Rehabilitation is a subject area that cannot be linked to a single occupational group. Many different professions can contribute in different ways in the rehabilitation. For Eikholt, it is

important to have a good mix of professions that together can give the users a comprehensive and good service.

The interdisciplinary approach is simply about creating collaboration between different subjects or professions. Interdisciplinarity is characterized by the subjects being integrated and sliding into each other to a greater or lesser degree, and that there are smooth transitions between different degrees of interdisciplinarity. We use the term multidisciplinary work when we from different professions work on the same task, but the subjects are kept separate (Store norske leksikon, 2018)



The work at Eikholt often consists of both forms of collaboration. But there are obviously many interdisciplinary links between, for example, the professions within vision, hearing, and communication. The interdisciplinary approach enriches the level of knowledge and new connections are discovered. When we work integrated interdisciplinary, the subjects come together in a larger unit, the professionals work with concepts, procedures and perspectives from several subjects at the same time, and the subjects are no longer clearly separated. Planning rehabilitation measures is an example of this. When we work interdisciplinary, this means that, for example, visual professionals with their cutting-edge expertise collaborate with hearing professionals with theirs to optimize all the sensory functions of a user. The vision and hearing function is mutually supportive, and a successful rehabilitation depends on good cooperation between the subjects. In addition, it is an important point that several employees at Eikholt master sign language and that there is good cooperation with the interpreting service.

It is a principle for the work at Eikholt to safeguard cutting-edge expertise in each subject area and at the same time facilitate interdisciplinary and multidisciplinary forms of collaboration. **For Eikholt as a national resource center, specialists are more important than generalists.**

Rehabilitation or habilitation

Habilitation is about learning new skills, while rehabilitation is about regaining lost skills. However, the general principles are common to both habilitation and rehabilitation. We have therefore not seen it as important in this document to constantly show this distinction, but we have chosen for the sake of simplicity to use the word rehabilitation throughout.

Congenital or acquired

See the possibilities of the individual instead of dividing into groups

In the Eikholt model, we have chosen not to distinguish between congenital and acquired causes of combined impaired vision and hearing function/deafblindness. This is because it can be difficult to define whether to call a diagnosis congenital or acquired. If the cause is congenital, but the functional effects come later in life, this division does not automatically make much sense. In that case, it had to be in the discussion about how early to take measures. We would generally argue that there are good effects of early intervention, regardless of whether the cause is congenital or acquired. There are so many variations within each of these two groups that it is unnatural to use such a rough division. The variations can be greater within each group regardless of this division. An important variable is, for example, when in the life cycle the reduction in visual function and hearing function became noticeable separately. Another important variable is the degree of disability, which varies from the visually impaired to the blind and from the hard of hearing to the deaf. There are also large variations in other physical, mental health, cognitive and social conditions to cope with the challenges. Eikholt has therefore in principle chosen to look at individual differences instead of dividing the group into these two main groups.

Eikholt offers services to everyone regardless of whether they can be defined as congenital or acquired. Much of the work takes place in collaboration with close people. For people under the age of 18, this is very important. In this report, we have used the word "user" without elaborating on this every time, but in many cases the term "user" also includes important close people.

The Eikholt model

The Eikholt model is a description of the practice in our business and why we do as we do. It is a description of what we want to be. We have seen the need for such a description because we have experienced that there is something that is clearly beneficial in what we do. We receive regular feedback on this from the users of Eikholt. But we have also seen it in a comprehensive user survey (Eikholt, 2020a), in several surveys among employees and in all the evaluations after each course. There is something positive in the "walls" at Eikholt that is worth taking care of and that can certainly be further developed. To obtain this "something", we have set ourselves the goal of describing the practice and the rationale for this in the form of what we call the Eikholt model. The purpose is to make visible, make aware and take care of what is good for it to last and further develop it into something even better.

To describe what the Eikholt model is, it became necessary to look more closely at what users say about Eikholt and what makes it feel good. Processes internally among employees have given us descriptions of what they think is important and what they experience works well. We compared these answers with what is Eikholt's official mission on behalf of society. In the development of the model, we have used recognized theories about rehabilitation of people with combined visual and hearing impairment/deafblindness.

Eikholts approach to rehabilitation is to build awareness and competence in the users

Eikholt is a national resource center. Traditionally, people think of such national centers as having the expertise of specialized professionals. When the center works in a system -oriented way, it means that its task is to pass on its expertise to local services that are responsible for the rehabilitation. This is a top - down model (Haidar & Rusevski, 2019) where the idea is that the general competence about people with deafblindness can be disseminated and put into practice in the local community.

A more user-focused approach is to build the competence of the user himself and of the user's close people and other helpers. This is an approach that works well when it is important to see each user as unique. The understanding of needs and measures must be individualized, and thus the amount of general competence that can be transferred is limited. With this starting point, the most important thing is to strengthen the user competence for the person in question to gain insight into their own situation. The goal is for the competent users and their close relatives to be able to use the local support system to achieve mastery in everyday life and participation in society. In this way of thinking, Eikholt becomes a resource for strengthening user competence.

In this bottom - up model (Haidar & Rusevsky, 2019), strengthening the user is the most important thing. This takes place through purposeful dialogue, education and training, where you build the users' competence, security and insight and thus the opportunity for control over their own situation. There is a lot that can be done to achieve this. We follow a model that consists of four phases:

PHASE 1: NEEDS MAPPING

- Information about Eikholt
- Obtaining information about diagnoses, treatment, and measures
- Mapping of wishes, needs and activities

PHASE 2: FUNCTION MAPPING AND OPTIMIZATION

- Mapping of function and skills (vision, hearing, communication, etc.)
- Optimization of function and skills (vision, hearing, communication, etc.)

PHASE 3: INSIGHT AND MASTERY

- Individual adaptation of various measures and design of individual rehabilitation plan (goals)
- Education and training to gain increased insight, skills, and knowledge

PHASE 4: PARTICIPATION IN SOCIETY

- Local implementation and support
- Follow-up

The foundation of the Eikholt model

Eikholt focuses on the user-focused approach. Much of this takes place through individually tailored NAV adaptation courses and individual services under the specialist health service. This makes Eikholt a very user-friendly service. Much of the offer is given in direct contact between Eikholt and the user (including close people), and it is given on the user's terms.

In the user survey, it is emphasized that users experience employees as «fantastic». This means that they experience being met with respect, hospitality and with good attitudes.

"Those who work there have an understanding and empathy for our needs and are able to fill the needs with good services" (Eikholt, 2020b). This shows that the center is characterized by a positive view of people. Users are met where they are, listened to and taken seriously by being allowed to influence decisions that concern them. Our values are about creating an Eikholt that is characterized by security, high competence and spacious creativity that shall create the environmental conditions for personal development with a strong self-image and control over one's own life. **The values safe, competent, and creative are the foundation of the Eikholt model.**

In practice, this means that employees have a conscious attitude that users themselves can, and are responsible for, influencing their own development, and that they can change the conditions for their lives and their own performance. It further means that there is a basic acceptance of involving the user to develop their own rehabilitation plan. There are many examples of how an environment can close, limit and hold down the potential that all people carry. Alternatively, an open and safe environment can liberate and convince us that in all people there is a capacity that can be developed. Involvement and real participation create motivation. Giving and gaining trust is very crucial for how we humans are motivated and towards strengthening our self-image. We say that it is important that the user (including close people) is seen and heard. The experience of being significant, competent, and equal is fundamentally important for everyone. Motivation must come from within. You cannot give people motivation, but you can contribute to the process of finding it.

The conditions for this are openness and security. At Eikholt, great emphasis has been placed on creating such an environment, both physically and socially. Users say that they experience "security and openness". "I am very fond of Eikholt, so my wife and I are there several times a year. Simply our second home". Many emphasize the importance of board and lodging in this context. "Good accommodation and very good food. Good outdoor area that feels safe to travel in, and I feel taken care of". "Board and lodging are excellent!" (Eikholt, 2020b). At Eikholt, lunch breaks are a key element in creating a warm, inclusive

environment. Employees and users have lunch together in bright, cozy rooms. Eating is about more than just getting full. The social gathering point that the meals are represents is important for the community and creates well-being. It is also a unique meeting place where the conversations create closeness and insight. The meal is closely linked to mental health, well-being, joy of life, and has cultural and social significance. Therefore, the kitchen, dining room and living room are an important element in the Eikholt model.

In the user survey (Eikholt, 2020b) it is pointed out that the pool and the physical environment around Eikholt invite to physical activity. There are safe paths for training and exercise around the center. Physical activity promotes health, improves mood, provides energy, and reduces stress. It can prevent some mental ailments and can in many cases be used in treatment together with other treatment methods (Ehn, 2020).

Based on a user survey, we have collected descriptions of what characterizes Eikholt, what is typical Eikholt and what they appreciate about Eikholt, 2020a). We have also had internal meetings with group processes with all employees. They have described how they view their tasks, what works and what should be further developed. The sum of these descriptions has been systematized and compiled into what we call 10 Eikholt principles or a practical expression of the Eikholt model.

10 EIKHOLT PRINCIPLES

1 Low threshold service
By this we mean that there is direct contact between Eikholt and the person seeking services. There are no requirements or formalities to prevent you from contacting us. The work of obtaining the information that is necessary for us to be able to assess whether we can provide service should be on us. If the applicant is not in our target group or is best served by another service, we will be helpful in contacting others. We should be able to be the first contact for people with combined sensory loss/deafblindness.

2 Expert on your own life
This means that our basic attitude is that it is the user's own assessment of wishes and needs that forms the basis for our work. The user must be seen and heard in all matters concerning him/her. In many cases, the best results are achieved in a respectful interaction between professional and user. Here it can be enlightening to distinguish between goals and instruments/measures. We believe that the starting point should be that the user is always the expert on what is important for experiencing quality of life and meaning in one's own life (quality of life goals), while professionals often know best how to work to realize these goals (measures). Clarification and prioritization of the individual's quality of life goals must therefore, together with a comprehensive mapping of status and prognosis, form the basis for any choice of measures.

3 Equality
At Eikholt, everyone is equal. We are a large "WE", a collection of users, close people, interpreters, companions and staff. This means that we are together and collaborate on the services delivered from the center. This presupposes that we have made sure to establish a

communication that works. This is done by optimizing the visual and auditory functions, as well as using supplementary or alternative forms of communication. Examples of this are sign language, haptic communication and technical aids. Interpreter/companion[1] is therefore very important when they are at Eikholt.

4 Users' Advocate
In the meeting with society and the administration, we work to ensure that users meet their understanding of their situation and gain an impact on their rights. Where rules and guidelines are against users' needs, we will work to change them.

5 Create an arena for security and development
Some users have mentioned Eikholt as their second home (Eikholt, 2020a). It is our goal that all our users should be able to feel that way. In a warm environment, everyone should feel safe and welcome. Through respect and equality, everyone should experience being seen and heard. This is a prerequisite for learning and personal growth.

6 A meeting place
Eikholt will be a social meeting place where everyone can participate and communicate with others based on their own prerequisites. It is a goal that the users of Eikholt should be able to establish lasting contacts to strengthen their own development. Through giving and receiving experiences, everyone should feel valuable and significant.

7 Build your own insight
Insight into one's own situation is the key to independence. Through knowledge, insight, learning and training, the user must achieve a proud and lasting self-image. Existential (meaning of life) themes should play a central role in all parts of the business.

8 Build knowledge
We often say that knowledge is power: for example, knowledge about laws and rights, how society is organized and about the aid apparatus. Through knowledge about their own diagnosis and prognosis, about vision and hearing function, communication and language, technical aids and what consequences it has for activities in different environments, the user must take control of their own situation. An element in this is also to be able to convey this knowledge to others in the local community.

9 Develop skills
The user must learn strategies and techniques to master everyday life, i.e., learn to anticipate challenges and plan measures. The user must learn to use aids and compensatory techniques in different activities.

10 Knowledge of aids
The interpreting services (1) and technical aids are important tools for achieving equality and participation. This includes knowledge, and possible use of new technology. Therefore, we

[1]The interpreting service in NAV covers interpreting assignments and companion for people who have deafness, deafblindness and hearing loss. (Nav, 2020)

must constantly be looking for new opportunities and explore this in our own innovation projects.

Illustration of the principles

The figure shows the 10 principles in the Eikholt model. Steps 1-4 reflect our attitudes, 5-7 include the social and existential aspects, while 8-10 are from a perceptual and physical perspective: senses, technical aids and activities.

Theoretical point of view for the Eikholt model

Can the Eikholt model be summarized in an overarching theory or philosophy that describes Eikholt's point of view? What is closest is what is gathered under the concept of person-centered care (Santana et al., 2017) or in our context « **person-centered rehabilitation** » (see below). In our model, rehabilitation is a targeted process:

1. Rehabilitation is more than the measures. The measures are really just tools for realizing important individual goals. Rehabilitation also includes maturation and cognition processes, reorientation, new mastery and much more.
2. Rehabilitation will most often be multidimensional, with different sub-processes running parallel in different areas of life simultaneously.

We believe that the understanding of "rehabilitation" in the Eikholt model is in accordance with the official definition of (re) habilitation. “Habilitation and rehabilitation shall be based on the individual patient's and user's life situation and goals. Habilitation and rehabilitation are targeted collaborative processes in different arenas between patient, user, relatives and

service providers. The processes are characterized by coordinated, coherent and knowledge-based measures. The purpose is that the individual patient and user, who has or is at risk of having limitations in their physical, mental, cognitive or social functioning, shall be given the opportunity to achieve the best possible functioning and coping ability, independence and participation in education and working life, socially and in society" (Helsedirektoratet, 2020)

But the Eikholt model is also a description of Eikholt's place in the **rehabilitation process** for people with combined sensory loss/deafblindness. What is Eikholt's role? And not least what happens "after" the stay at Eikholt. We have put "after" in quotation marks because there is rarely a clear "after". Most people need Eikholt's efforts repeatedly for the rest of their lives. We have chosen to describe this understanding of Eikholt's role in the form of a **user journey** (see page 18).

Person-centered rehabilitation

Personal center rehabilitation is a term we use in this model. It is derived from the term «person-centered care» as described in the health service (Santana et al. 2017)) and the English «empowerment» used in rehabilitation (Johansson, 2017). It involves a partnership between the user, relatives, and professionals in the rehabilitation. Based on listening to the user's history, a joint rehabilitation plan is written that includes goals and strategies for implementing a short- or long-term effort.

Many professional circles claim that they already work person-centered. But working consistently in all situations and every day in accordance with this philosophy is difficult and requires awareness of each individual action, good practice and working method and that the overall organization is adapted to this. This presupposes conscious effort and continuous learning, and extends far beyond a value-based document.

There is a big difference between describing deafblindness and living with deafblindness

It is about seeing the user as an expert on their own life, a resource person, with abilities and needs. The qualities and abilities that characterize a person can be noticed, but also neglected, they can be strengthened or inhibited by the person himself and/or other people. Involvement and partnership require mutual trust between the user and employees at Eikholt. It requires awareness that this relationship can become asymmetric. Professional knowledge is often linked to power and thus more responsibility. This must be balanced against the user's right to be heard and seen, the right to autonomy and integrity.

The most central part of the Eikholt model is the idea that work is a partnership. It is about mutual respect between the user and the professionals and for each other's knowledge. On the one hand, the user's and relatives' knowledge of what is important for the experience of quality of life and what it is like to live with the double sensory loss. On the other hand, professionals' knowledge of rehabilitation, which is a more general knowledge. Today we see it as a human right to decide over our lives and bodies. Person-centered rehabilitation

means attributing both rights and responsibilities to the user regarding their own rehabilitation.

Self-determination

We believe that the user's dignity is an important concept here, and in connection with rehabilitation will say that the user's dignity is largely about the user's right, duty and responsibility to determine content in their own lives, within social, legal, ethical, moral and economic framework that applies to all of us in society.

User authority is a prerequisite for safeguarding user dignity. This means that we must ensure user management and user participation. By that we mean that it is important to:

- User management in the form of informed choices in setting goals for the rehabilitation process.
- User participation in the choice of measures to achieve the goals.

The consequence of this is that Eikholt must see the person seeking help as an active partner, with the necessary knowledge of what is required of a rehabilitation that matches the wishes and needs of the person. This does not mean that the person becomes a "customer", and that the rehabilitation must deliver everything according to his or her wishes. The partnership involves a shared responsibility, and the rehabilitation must be adapted to both parties' goals, competence, and resources.

In rehabilitation activities, the meeting between user and professional is fundamental to shaping the partnership, as it is always based on the user's history. Listening to the user's stories about their own life situation and combining this with mapping is the prerequisite for person-centered rehabilitation. This requires a high degree of skill, and it can take time to create the trust that is necessary for users and loved ones to dare to trust the professionalism of employees. In person-centered rehabilitation, this process can lead to a "contract" or "personal rehabilitation plan". This is a common document for users, close people and professionals and provides support for a common understanding of goals and how the rehabilitation is to be implemented and secured. The process should take place with the involvement of close people.

A common comment is: "I always listen to users." But there is a big difference between hearing and listening. Employees often hear users, and their loved ones say something or attract attention - but stopping and listening requires more and is more difficult. At Eikholt, the focus in communication is the user's experience and interpretation of life, of how the combined sensory loss affects daily life and what opportunities the user has in their life situation. Bringing out these stories forms the basis for planning the rehabilitation, but this process can also in itself be healing and increase the possibility of achieving the goal.

Another important component in the Eikholt model is documentation of the history, assessments, and measures in the rehabilitation plan in the user's journal. This documentation must be " live ", continuously updated, be available to the user and follow the user through the rehabilitation process. A main purpose of this is that the user and close people should not have to repeat what was previously said every time the person in

question is in contact with Eikholt. Another point is that this information should be gathered and easily accessible to everyone involved.

The life-world

The life-world is the world we live our daily lives in and which we, unreflectively take for granted. Here we have our attention in everyday activities. We share the life-world with other people, animals, and things. This is where we communicate and socialize with others, carry out various activities and life projects, think, feel, gain knowledge and experiences. The life-world is not a private world. It is a social world with which we have a historical and cultural relationship. It is complex and nuanced, and we must relate to it as long as we are alive (Berndtsson, 2001; Bengtsson, 2006; Johansson, 2017).

Past experiences and habits affect our way of acting and it is from this store of experience that we interpret, understand, and create meaning in our own and others' actions. Our experiences are not static, they are constantly changing. People who get a disability do not just get a reduced physical change. The approach to the world in which he or she lived before the physical change has also changed. Past experiences can change character in new contexts and through new experiences. This can create other ways of performing activities, and/or it can change social contexts and relationships.

The lived body

We have chosen to use the theory of the lived body as a framework for understanding the rehabilitation processes. Words such as "the lived body" are used as a symbol of the whole person and various parts of a person's life can be referred to as "the existential body", "the body of perception", "the body of activity" and "the social body" (Berndtsson, 2001; Johansson, 2017).

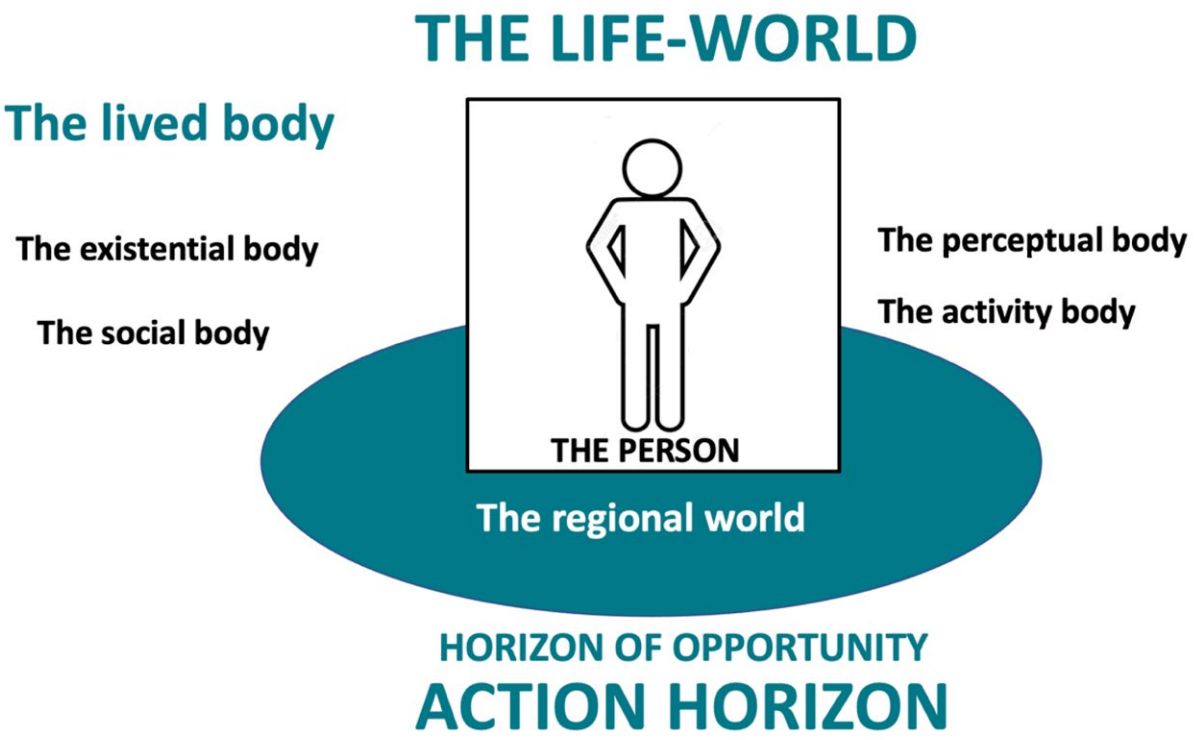
Person-centered rehabilitation puts the user in focus and the rehabilitation is based on the user's needs, priorities, and goals in the current life situation. In person-centered rehabilitation, the body is seen as an object and subject that reflects our relationships and experiences of the world we live in. When the body functions and is in balance, we take it for granted, but in case of imbalance, when e.g., vision and hearing are impaired, our relationship to the world and to the people we live with changes. How the users and the people they live with experience, interpret, and influence everyday life can be experienced differently. It is not only the physical body, but also other dimensions of the body that must be involved in the rehabilitation process. It is therefore important with dialogue between the user and the professiona(s) to gain insight into the user's needs, wishes, priorities and expectations, but also the psychosocial, cognitive, and practical prerequisites for a relevant rehabilitation process.

At Eikholt, as mentioned, we have started from the "theory of the lived body" to be able to take part in the users' experiences of what it is like to live with a changed body. Most users who come to Eikholt have a progressive disability. This means that the body changes over time. One does not know when the changes will come. Users and loved ones live in an insecure everyday life. Rehabilitation is a process that is to provide knowledge about the user's body's opportunities to be able to access what the user has difficulties with and/or misses in everyday life. Berndtsson (2001) believes that in planning a rehabilitation process,

one must consider the lived body. The lived body is a body intertwined by the existential body, the perceptual body, the activity body, and the social body.

The existential body is connected to existence, how the user and others perceive people who are different, human dignity, identity etc. The body of perception describes the perceptual changes that prevent us from accessing the world and our relationships to it. The activity body is the body that has learned and is learning to cope with the everyday activities. The social body describes the user's relationship to himself, family, and others in social contexts. In a rehabilitation process, one must merge all the different "bodies" into a whole to face the world in a different and better way.

In the theory of the lived body, we use the word "horizon" about the possibilities the user sees for his own life. A narrow horizon gives little hope for the future, while rehabilitation will move this horizon to an expanded horizon. These are processes that are mainly about the user himself, his own self-image and belief in the future. We refer to this as a horizon of opportunity. To get there, the term action horizon is used as a description of the processes and activities that are part of rehabilitation (Berndtsson, 2001; Johansson, 2017).



The user journey

In principle, the rehabilitation of people with disabilities is a targeted process in which different actors play different roles. It is important that rehabilitation is seen as a multidisciplinary field in which many occupational groups have a lot to contribute. But there is also a big challenge in this. Different understandings of rehabilitation and one's own role in this, unclear routines and responsibilities can easily lead to the process falling apart and the aid apparatus acting as a jungle where it is difficult for the user to find out.

Eikholt sees himself as a key player in the rehabilitation process for people with combined visual and hearing impairment/deafblindness. This means that we must see our place in the holistic interaction, be clear about our role and know how to cooperate with the other actors. Here we will describe Eikholt's role and choose to do this in the form of a «user journey». A journey that describes the process from the user's perspective.

An illustration of the Eikholt model

The figure shows a schematic picture of the user journey at Eikholt from the first needs mapping through optimization and training to participation in one's own local environment.

Rehabilitation measures are often described as a journey in several phases. But there is no clear distinction between the different phases, they must constantly overlap. We have chosen to divide the journey into four phases:

- Phase 1: Mapping of needs
- Phase 2: Function and optimization
- Phase 3: Insight and mastery
- Phase 4: Participation in society

Phase 1: Mapping of needs

We have placed great emphasis on a low threshold for contacting Eikholt. The inquiry can be made by telephone directly to Eikholt or by registering a request for services on Eikholt's website. When an inquiry is registered, it is processed on an ongoing basis.

The inquiry

After Eikholt has received an inquiry, responsibility for obtaining information is distributed. This is done by one of Eikholt's advisers contacting the user for a mapping interview with the aim of gaining insight into the user's needs and wishes.

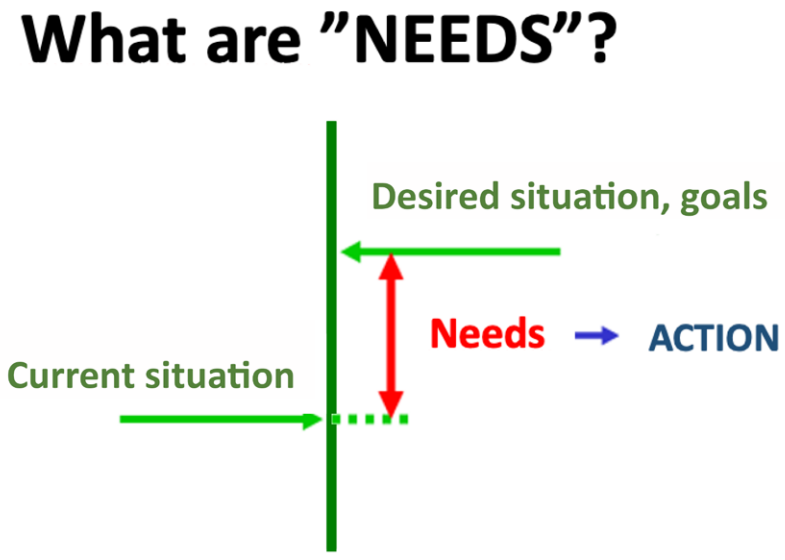
Dialogue

When inquiry is received from new users or if the progression of the sensory loss has make it more difficult to manage daily life, home visits will often be part of mapping needs. Another important purpose of the home visits is to be able to inform about Eikholt's services, inform about the practicalities of participating in courses at Eikholt, start building a relationship and get to know the user and relevant close people. The focus here is on both the functional and the practical, as well as various psychosocial conditions around the user.

"Need" can be defined as a deviation between the current situation and the desired situation (based on Lie, 2001).

It is a widespread problem in rehabilitation that the processes are not consciously and clearly anchored in what **the user** sees as important goals for the experience of quality of life and meaning (Berge, AR personal communication, 5 October 2020). What we refer to “quality of life measures”. If a "mapping of needs" is carried out without a clarification of the user's quality of life goals, it will easily be the aid apparatus' understanding of goals that is unknowingly used as a basis. And it can involve overriding the user's values and personality. By this we mean that a clarification of the user's goals is fundamental for the entire rehabilitation process.

In the Eikholt model, we have respect for the user's own assessments in the needs mapping and what should be the goals for our services. There is a lot of energy and important motivation in the user's own wishes and goals.



”Mapping of needs” is carried out with a clarification of the user´s goals. This is fundamental for the entire rehabilitation process.

This is energy and motivation that can sometimes bring the user significantly further than professionals initially envisioned. Professionals who see it as their task to " reality -orientate " then run a risk of stifling motivation and cutting off opportunities. We believe it is the right approach to take as a starting point the wishes of the user, but through dialogue and process over time build the user's understanding of what it takes for this dream to possibly be realized. Together with the user and the dream as a guide, we will develop concrete and realistic sub-goals along the way. Then, during the further process, the user will often develop an understanding of whether the wishes are realistic or whether he/she must be content with realizing some of the sub-goals. Such orientation of reality, which "comes from within" is far more dignified and constructive than that which occurs in that authority figures often stifle deeply personal desires.

Mapping a person's wishes/goals and need for rehabilitation can be a demanding task because these can be hidden and not readily available. Motivation and wishes may vary and change over time, depending on, among other things, what information, knowledge, and insight you have about your own situation/your combined sensory loss.

We strive to provide the user with information about our services and opportunities. This is something that is followed up in introductory courses, which is often the first course new users at Eikholt receive. When the user comes with his own life experience, we must expect and respect that the user has his own opinions, and we must ask for them. It is important that the user's own choices are decisive, based on their wishes and needs. The purpose is to make the user more aware in relation to their own situation and their own opportunities, perception of values, wishes, priorities and needs. The mapping shall take the form of a dialogue between user and professional so that the user is able to choose rehabilitation goals that are motivating, with realistic sub-goals, which are in a reasonable relationship to their own identity and ability.

Phase 2: Function and optimization

The second phase is about mapping functions and skills with emphasis on the senses, communication and the psychosocial. Furthermore, it is also about testing aids and planning measures. We have chosen to call it "mapping and optimization of functions". The purpose is to optimize the functionality in the areas and activities that the user defines as important. The choice of rehabilitation goals must therefore be linked to the person's own priorities, wishes, and needs. By doing this, we have taken the consequence that rehabilitation is also about choosing life values. Since many of the people with combined sensory loss have a diagnosis which means that the visual and hearing impairment progresses, it is important and valuable to have regular surveys of needs and function. Part of this work is done in what at Eikholt is called the AV clinic, which stands for Audio = hearing and Visio = vision.

AV clinic

Eikholt is equipped to map vision and hearing functions in those users who still have residual vision and/or hearing that is used in everyday life. For those who are blind, it is extra important to map the hearing function and vice versa for the deaf. This applies to most users of Eikholt. Even though they have small remnants of function, it is important that these are optimized and that together they explore how the residual functions are used appropriately. This happens in the AV clinic. It is staffed with professionals who have cutting-edge expertise and equipment for mapping vision and hearing function.

Examples of current measures for optimizing the senses are testing and adapting hearing aids, special optics, or other specific aids to improve the possibilities of carrying out an activity. What makes the work in the AV clinic special is the close collaboration between the professional groups. For example, there are very special needs that must be considered in the adaptation of a hearing aid when a person at the same time has poor vision and must rely on sound impressions when orienting and moving. The unique thing about the AV clinic is that the work takes place in close collaboration between the user, hearing specialists and vision specialists. That the user understands their own function and how it is affected in different situations is a key goal for the company and forms the basis for Phase 3 in the user journey. User insight and understanding requires that time be set aside for explanation and learning while the mapping of needs and functions is ongoing. Therefore, it is important that detailed plans are made for the communication to work. Interpreters, sign language staff and technical solutions for communication are part of this arrangement.

> A combined sensory loss cannot be understood as vision plus hearing. It is an interaction between the senses that requires an understanding of how the measures affect all the senses.

The AV clinic must be able to serve different types of users of all ages. This places special demands on the equipment and skills of the staff.

Phase 3: Insight and mastery

Phase 3 focuses on the whole person. Here is the person with their desire to be able to perform activities in the center. The phase is about competence building around mastery. This must also aim to provide help and insight into, as well as acceptance of, the existential aspects of permanent disabilities. It is important to focus on the strengths, get the user to see and believe in their own abilities to solve problems, to think of solutions and see opportunities.

Adaptation course
People with combined visual and hearing impairment/deafblindness and their families, have the right to participate in adaptation courses and Eikholt has a national responsibility for these courses. For our user group, it is especially important that resources are used to disseminate knowledge that gives users insight into their own situation. The user must be given sufficient insight and information about opportunities and limitations in relation to their own functional status to be able to make their own choices. It is important that this happens as a process through dialogue and close cooperation between the user and the professionals. At Eikholt, this takes place largely in the form of adaptation courses and every year a course catalog is prepared with an overview of current courses. The adaptation courses can take place at Eikholt, at the user's home, or at the user's workplace or study place. Adaptation courses are given both as **individual courses** and as group courses.

Introductory course
Introductory courses are aimed at new users of Eikholt, or for users who have experienced significant changes in vision and hearing function. It helps to form an important basis for other courses/training. The course can include a visual and auditory pedagogical mapping, conversation with a social worker, mapping of communication, conversation about activities in daily life, testing and application for aids and contact with the regional services.

Group courses and individual courses
Eikholt holds group courses that are more theme-oriented, while other individual courses are given to meet the individual's special needs. Examples of topics for such courses are:

- Braille
- Communication
- Mobility/accompaniment
- ADL - activities in daily life
- ICT
- Smartphone/tablet (such as iPad /iPhone)
- Services for couples and families

Close relatives are offered courses to increase their competence in combined visual and hearing impairment/deafblindness, get information about the consequences of double sensory loss by attending park courses, family and network courses, etc. The goal is for course participants to be able to preserve and develop their natural family network. Close relatives include close relatives as well as relatives who have regular contact with the person in question and in this way can be said to have the function of a close relative.
The service is "tailored" by Eikholt as far as possible, i.e., it is adapted to each individual, and a plan is prepared based on need.

Follow-up course
Combined visual and hearing impairment/deafblindness is usually a progressive disability. Therefore, there will be a need for follow-up in the form of supplementary courses that can be spread over a longer period to provide the necessary time to acquire new knowledge and to practice or adapt to changes in the disability and what is being learned.

Phase 4: Participation in society

Participation in society is mainly hindered by these challenges (Johansson, 2017):

- poor access to information about rights, social efforts and what is happening in society
- loneliness related to changes in the life situation
- changed state of health and level of function
- inactivity and activity services that are not adapted to individual wishes and needs
- failure to meet social, cultural, and existential needs
- lack of meeting places to meet peers
- disability benefits without the introduction of other measures
- availability in the environment

The Eikholt model is a description of what Eikholt perceives as its role in what is often called a process with several people involved, where Eikholt is an important player. Then one must also have an understanding of cooperation with other actors and how this can be taken care of, and not least what happens "after" the stay at Eikholt. Most people need Eikholt's efforts repeatedly for the rest of their lives. We therefore see that there is a need for a plan for which measures are relevant. Normally, this should be part of what is called an individual plan[2].

Planning work

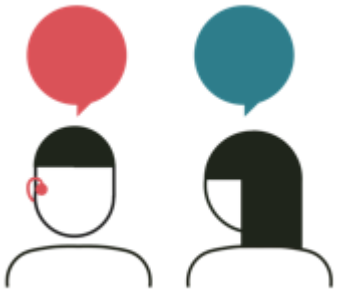
Everyone who needs long-term and coordinated health and care services has the right to have an individual plan prepared (Helsedirektoratet, 2020). The plan should only be prepared if the person himself wishes. The initiative to create an individual plan can come from the user himself or close people, but the main responsibility for preparing individual plans lies with the service apparatus. The municipality has the main responsibility for coordination when people receive services from both the municipality and the specialist health service. The specialist health service shall participate in the planning work, and it shall also report the need for an individual plan to the municipality. We have chosen to call our contribution to an individual plan an "Eikholt plan". The Eikholt plan can be included as a natural and important element in the user's individual plan.

Participation-oriented measures

Phase 4 is very much about participatory measures. Much of this happens locally in collaboration with local services. In the first three phases, the rehabilitation process has been about optimizing the opportunities for the user, while in the participation-oriented part it is about the person in relation to the environment. The goal must be for people with disabilities to be able to participate as much as possible in their own family and local environment, as well as participate in society in general. Measures can be, for example:

- *environmental adaptations*
- *training in alternative means of communication to close people*
- *information for close relatives about double sensory loss*
- *guidance and counseling to the social and professional network around the user*
- *courses and education for local professionals*

[2]Individual plan (IP) is a coordinating plan that the user, together with relevant actors, creates to define rehabilitation goals, efforts, and division of responsibilities between the various actors (Helsedirektoratet, 2020)



When users leave Eikholt, the idea is that the rehabilitation process will continue in the local environment. This is usually in the home municipality. Depending on where you are in life, it may be relevant to take measures at school, at work, in your free time or at home. Many of Eikholt's users have servicesfrom several different services organized regionally and locally. Among others, Statped (State special education service) and NKDB's regional centers. For the users, it is important that these services cooperate with Eikholt and that the measures are continued.

Everyday rehabilitation

Everyday rehabilitation is often referred to as a paradigm shift in many municipalities in that staff go from asking what the problem is for the user to focusing on what are important activities in life, coping resources and rehabilitation (Helsekompetanse, 2020). Many municipalities that have initiated the service express that they have good experiences after start-up. There is great enthusiasm among employees with responsibility for everyday rehabilitation and several local resources, tools and aids have been developed (Hartviksen, 2014). This is also the thinking in the Eikholt model.

> We believe that the best spread of competence takes place by building up the user and letting the competence follow the user.

Experience shows, however, that there are several challenges associated with designing such a service (Fæø, Petersen & Boge, 2016). The employees in the municipalities usually experience the close interdisciplinary collaboration as professionally stimulating and developing, but it can also be experienced as challenging in terms of collaboration and clarification of new roles. Users benefit greatly from the fact that the service is designed according to their priorities and value this highly, but some feel pressured to live up to the staff's ideal of becoming self-sufficient quickly. We have experienced that some users call for consideration to be given to the fact that they are in a vulnerable situation with a limited opportunity to regain previous skills.

The investment in everyday rehabilitation in many municipalities must be interpreted as an expression of a way of thinking where one realizes that rehabilitation should take place in the environment in which the user lives, and with the user's goals and priorities as governing. In the Eikholt model, Eikholt plays a role in building up the user, but the effect must be extracted from daily life at home. The model has been valued by many people with dual sensory loss as beneficial in living rich and fulfilling lives, although they themselves shape their own everyday lives, are active and participate in social communities. They contribute their resources at work, for family and friends and in the local community. Quality of life is about experiencing joy and meaning, vitality and satisfaction, security and

belonging, about using one's personal strengths and feeling interest, mastery and commitment. Quality of life also provides health-related benefits such as better physical and mental health, healthier lifestyle choices, stronger networks, reduced risk of isolation and increased social support (Wahlqvist, Möller, Möller., & Danermark, 2013). Quality of life and well-being also strengthen resilience in the face of stress. Because one should not underestimate the burden of having a combined sensory loss/deafblindness. Many users report a significant loss of energy in the work of mastering everyday life.

In the work with the Eikholt model, we have emphasized strengthening and empowering the user. Eikholt will create better conditions for coping, but it is the user's local environment that has the greatest impact on the daily quality of life. Services and measures must be developed where the users live. Therefore, the competence must follow the user. People with combined sensory loss may be dependent on meeting many of their different needs in the local environment and being close to most things: public and private services, trade and services, social meeting places, cultural services and events, hiking trails and green areas. Such accessibility in the local community is fundamental to having the opportunity for an active everyday life where one can to a large extent function independently and manage oneself.

Finally, the Eikholt model is based on the basic question: "What is important to you?" Developing a combined sensory loss often means that you need someone to assist in everyday life. But that does not mean that you should lose your identity and the opportunity to be in charge of your own life. Throughout life, everyone should be treated with respect and met as the "whole" person that he or she is. Some may experience that in everyday life it is mostly about diagnosis, disability, and compensatory measures. Then it is important that at the same time there is attention to what it takes for you to still be able to master everyday life and experience having good and meaningful days. The Eikholt model emphasizes that this happens best in the local environment, but we experience daily that at the same time one must create conditions for this by strengthening the user and the local people.

This effort is like a circle in the Eikholt model where efforts from Eikholt play together with measures for participation in society.

The figure shows how the follow-up often shows that changing needs initiate new measures involving Eikholt.

Follow -up

Follow-up of people with combined sensory loss must be seen in a life course perspective. We must therefore develop routines for follow-up that ensure that changes in needs and function are captured. Many in our target group have progressive disabilities, which means changes over time. This means that the rehabilitation process can never be considered complete.

EIKHOLT AS A COMPETENCE SERVICE

Information work

The website and Facebook page are important communication channels for Eikholt to users, local services and professionals. We use the pages to share information and to be accessible to everyone. The website will function as a professional and practical tool for anyone who works with or is interested in the rehabilitation of people with combined sensory loss/deafblindness. The website is also the place where users and close people can find useful information about services from Eikholt and where to report their needs for courses. Every year, Eikholt publishes professional reports that cover various topics. We have called these
"Eikholt reports" and gradually constitute a collection of writings that can be used in information work (Eikholt,2022. www.eikholt.no)

Competence dissemination

Eikholt is a meeting place for both users and professionals. As part of our mission to spread expertise, Eikholt participates in several activities and arranges its own events. This is:

- Conferences at Eikholt
- Lecture/presentations at colleges and universities
- Lecture/presentations at national and international courses and conferences
- Publication in professional journals
- Participation in professional networks - nationally and internationally
- Internship for students
- Supervision of students and other professionals

In line with the philosophy that competence dissemination takes place best when it follows the user, the AV clinic is an important tool in disseminating knowledge that will benefit the individual user. It is arranged in the clinic for close relatives, regional and local professionals can follow the work when this is desired. With the user's consent, they can participate in the work via video and take part in discussions of which measures may be relevant. Of course, this must always happen on the user's premises, but there can be a lot to be gained from spreading insight and understanding in this way. It is our experience that this form of competence dissemination is very effective.

User data

Much of what belongs before Phase 1 is outside Eikholt, but Eikholt can play an important role in the work of finding users who need the service. Although many of those who are registered with combined visual and hearing impairment/deafblindness have received services from Eikholt, we reckon that there are still many people out there who belong to the target group and who are entitled to services from, among others, Eikholt, but who do not know about the service. There can be large grey and dark numbers.

There is constant research in the field of deafblindness. A good user database with relevant registration of health data and personal data is crucial for the service to the individual user. Eikholt's user database ensures good quality of the services of the individual user, and that it gives us information and insight about the group of people with combined visual and hearing impairment/deafblindness. The user database is of great use for research and innovation. Eikholt's user database is already a unique collection of data on people with combined visual and hearing impairment/deafblindness. We are constantly working to develop content and analysis tools in this database for use in research.

Research, development, and innovation (R&D)

Research, development work and innovation (R&D) are important for progression in the field. The field of rehabilitation is changing and Eikholt wants to contribute to knowledge development. We therefore believe that it is important for Eikholt to develop and maintain good national and international contacts and import knowledge that can be tested in its own research and innovation projects. We will, in collaboration with universities and colleges both nationally and internationally, participate in research projects to bring out new knowledge.

The research at Eikholt must be close to practice and contribute to a better practice.

One important area is impact measurement for follow-up of Eikholt's services. Eikholt has good experience of involving users in project work and is very keen to continue with it (Eikholt, 2020a).

The fact that the field is often referred to as research weak compared to many other fields must not prevent Eikholt from initiating research and development work (Dammeyer, 2014). There is no shortage of empirical competence and there are many employees who have relevant and good experience from R&D work. One professional has a PhD and many have an education at master's level and eventually more will come with formal research competence. By establishing collaboration with others, such as colleges and universities, good and valuable R&D work is conducted at Eikholt. Eikholt currently has a formal collaboration with the University of Southeast Norway (USN) and University of Örebro. Sweden on research and teaching of students.

Eikholt has good conditions for R&D work. These can be summed up as follows:

- Good knowledge of the field
- Good knowledge development among employees
- Interdisciplinary activities
- User focus
- Eikholt is a " living lab" because users can stay there over time
- The user database
- National and international research network

It is very important that R&D work is a continuous and integrated part of the business at Eikholt. What we know for sure about the future is that it will not be equal to the present. Competence and knowledge development is a continuous process that expires if it is not maintained and renewed. Therefore, our attitudes to knowledge and competence should be characterized by curiosity! We will never finish development! - And we are never done!

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EIKHOLT

NATIONAL RESOURCE CENTER FOR PEOPLE WITH DUAL SENSORY LOSS/DEAFBLINDNESS

Eikholt is a national center of excellence in inter-disciplinary and broad-based knowledge and training in the fields of combined vision and hearing impairment and deafblindness. The Centre is situated in beautiful surroundings near the city of Drammen, 30 km west of Oslo.

Target Groups:

- persons with combined vision and auditory impairment/deafblindness
- professionals
- family and close people

We offer:

- rehabilitation to professional life, studies, and everyday life
- training for alternative communication
- optimization of vision and hearing
- research
- training and adaptation to information technology
- seminars and services tailored for individual needs
- a meeting place for individuals, families and professionals

Eikholt is tailored to the needs of people with combined visual and hearing impairment by its lighting, contrast- and color conscious design, telecoil for the hearing impaired, and ice-free and guided nature paths. Eikholt is a resource center that will communicate expertise to universities and important parts of the official support system. Eikholt is a non-profit institution owned by the Eikholt Foundation and funded by the Government of Norway.

EIKHOLT REPORTS

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