

# Cornerstones of Close Cooperation





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**CORNERSTONES OF CLOSE COOPERATION**

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# Close Cooperation Supports Good Living

**T**he key to providing a good life for a person with special support needs is good interaction and cooperation between loved ones and staff. They should have a shared understanding regarding the ways they can enable the person with special support needs to lead a life of his or her choosing. Meeting loved ones requires an open and listening presence from staff members. Respect, empathy, and authenticity are crucial factors. It is also important to have trust, which is not born by itself. It is built by responsible interaction and in each unique encounter. Worrying for and taking care of your child is rooted deep in the role of a parent – even after the child has grown up. At the core of them is love, which should be appreciated and respected.



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# Presence, Openness, and Willingness to Listen: Keys to Trustworthy Family collaboration

MARJATTA TAMMISTO AND KATJA MARJAMÄKI



**Having good interaction and cooperation between loved ones and service providers are key factors to ensuring good quality of life for a person who needs assistance. Managers and loved ones should have mutual understanding on how to enable the person who needs assistance to lead a life of their own design.**

**S**ituational sensitivity and pausing to be present are essential skills to have when meeting other people. Stepping into another person's shoes may open minds to understand and find the right words to use. Imagine visiting a health care unit with your child and wondering about something concerning his or her health. In a situation like this, you would be very sensitive to downplay or dismissive treatment, whereas positive feedback would be like balm to your soul.

*"Everything may be done.  
Everything should be done.  
Every door must be tugged at,  
every moon reached for.  
There is just one condition,  
vital condition:  
A vibrating soul  
may not be trampled."*

TOMMY TABERMANN

### **Self-knowledge Is Important: Personality as a Tool**

Working with people is the type of interaction, where it is important to understand your own personality and relationships. Eric Berne (1910–1970) developed transactional analysis, a theory of personality and interpersonal transactions, which may be applied at least partially as a tool for examining yourself, your ego. Berne talks about ego-states, that are the Child, Parent, and Adult state.

The Child state is grounded in our own childhood and the experiences we have. The reaction patterns born in childhood are rooted deep in us as our "inner child". Berne divides the Child state into negative and positive.

Negative is displayed when we are, for example, tired or stressed and do not have the energy to control our behaviour; we throw tantrums, explode, give silent treatment, run away, or avoid things. In commonplace situations and interactions, we repeat this learned pattern of behaviour. We often talk about "falling into childlike behaviour" or saying things before we have time to think about what we are saying.

The positive Child state in us is the spice of life. It brings forth joy, humour, gentleness, openness, creativity, and excitement. A positive, light approach to life, the skill to give truly positive feedback, exuberance, and cultivating goodness – all of these have roots in our childhood experiences.

We also present the Parent state, which reflects the childhood experience we have of our own parents. Berne talks about controlling or caring parents. A negative approach to life may stem from having experienced a distant or overly demanding parent. “This is not going to work, why bother” is an attitude that may be based in childhood experiences. Inflexibility, mechanical sticking to rules, and strict level-headedness come from a controlling, demanding parent.

The caring Parent in us grants us the skill for empathy, understanding, and caring. It also brings forth empowering values and traditions. If you have been cared for and loved as a child, you are able to show those qualities as an adult with your family, friends, surroundings, and work. A caring attitude also includes the ability to be responsible for yourself, for others, and for your assignments.

The Adult in us is born out of recognising the Child and Parent states. By recognising them, we can grow and develop our personality. Self-knowledge is adulthood, the basis for a healthy and balanced self-esteem. When we recognise the good in ourselves, we can strengthen and value it. Recognising and understanding our own weaknesses grants us the opportunity for development. Furthermore, learning new things, interacting with people, and having relationships are all important building blocks for adulthood.

*“So, walk with open and curious eyes,  
and find your hidden self!”*

### **Interaction Is an Artform**

In any situation that involves interaction, both parties are responsible for how successful it is. Erving Goffman spoke about face-work: people should meet each other so that they can save face even in difficult interactions. We also talk about allowing for a dignified retreat. Dignity means that you receive respect and appreciation from others.

What does it take to have a successful interaction? At least social skills, consideration, honesty, and tact. It is therefore important how we talk, what words we use, and what promises we give. It is important to note that only a fraction of our interactions is verbal communication. Body language, facial expressions, and intonation speak more than words – actually, interactions include a person’s entire life story. That is why it is smart to ensure that all participants have understood things the same way. Words do not always carry the same meanings for everyone!

We must be especially careful when giving negative feedback. Think about how you would like to receive that kind of feedback. Negative feedback is often perceived as an attack, which causes the recipient to react in defence, which hinders him or her from actually accepting the feedback. The old and

wise rule is that negative feedback should be given in private and positive feedback publicly.

Gossiping has a bad reputation; it is often perceived as speaking ill of someone or something, which it often is. But could there also be positive gossip, speaking and spreading good? That would have an uplifting effect on the atmosphere and activities. It could also serve as a tool in creating "atmosphere".

*"Good may and must be spoken behind people's backs and in front of them! Positive gossiping breeds good things!"*

### **The Power Over Your Own Life Should Be Yours Alone**

Loved ones and service providers should have mutual understanding on how to enable a life of his or her own design for the person in need of assistance. Their role is to make things possible, not to decide on anybody's behalf.

By diving into another person's life, it is possible to find the things they appreciate at that time. These things are what form that person's individual good quality of life. These things may be completely different from what is important or typical to you. We have different priorities, for example for spending. Consider and enable things from a perspective of "least harm".

Do we grant permission to express and handle emotions? Or do we act like we know it all? When a family member in need of assistance is moving out of the childhood home into their own place, he or she may feel homesick. Loved ones may experience worry and sorrow when he or she moves out. How do we respond to these emotions?

It takes time to adjust to new life circumstances. It is crucial that we acknowledge all emotions, respond to them, and give the right kind of support. We do not invalidate or dismiss but build trust and faith in the future.

*"My dreams are my dreams, not yours. I must make life my own truth. Walk beside me, hold the bridge, but do not live for me. Do not decide for me, what is good for me. And do not mourn for me, that my life became just this little life, because in God's announcement two columns read: Smaller lots are taken into consideration, too."*

AINO SUHOLA

## Taking and Assigning Roles

The laws of interaction include taking and assigning roles. If I take on a role, for example the role of the caregiver, I mentally place the other party in the role of the cared for. If I take on the role of the boss, I assign the other the role of the employee.

It is smart to acknowledge the role you take when you meet another person. By doing so you may find reasons for the way both of you behave. It also allows you to change your role and behaviour so that you can treat the other as your equal.

The role of a parent is strong and lasts a lifetime. It evolves as your child grows, becomes more independent, and breaks away from his or her childhood home, but as a role it is permanent. Taking care of and tending to your child sit tight with this role – even after your child has grown up. The heart and core of this role is love, which must be appreciated and respected.

### Touch

*“I waited for it so,  
longed in my distress,  
yearned in my agony,  
I knew it.  
And my wish was granted.  
She did not stay at the end  
of my bed,  
no, she came and touched,*

*touched and stroked,  
there also my  
torn self-esteem,  
a sister's touch  
a sister's love*

SIRPA LAMMI

## The Rules of Assistance Open Gates for Trust

Renowned social ethicist **Martti Lindqvist** (1945–2004) did considerable reflection on the work of a helper from an ethical point of view. According to him, aid and welfare work revolves around respect, empathy, concreteness, and authenticity. Trust is also important.

When working with people, respect for others and their lives is of the utmost importance. Everyone has the right to demand and receive respect regardless of his or her properties or status in the spectrum of life.

*“How does respect actualise even in the mundane but very intimate assistance situations?”*

Empathy refers to the ability to step into another person's shoes, to look at the world through his or her eyes. Empathy could be likened to a bus trip: From our own stops, we step into the bus as fellow travellers, look at the same scenery, travel together for a while, and then get off the bus. Until we travel together again, we lead our own lives.

Concreteness is especially important when interacting with a person who needs special assistance. Professionalism and strong know-how include the ability to explain things so that they can be applied to the listener's and fellow traveller's world.

Differently abled people are often extremely apt at noticing factitiousness. There is not much chance of bluffing, because your attitude and thoughts are reflected in your behaviour.

*"Authenticity – Do not fake it, do not pretend!"*

Trust is not born out of thin air, it is built. Every encounter and choice build trust. Trust is built like a tower of building blocks: block by block, meeting by meeting. Just one mislaid block, careless and inconsiderate meeting, may cause the whole tower to collapse. You must start at the beginning if you wish to build it anew.

*"Trust – it just needs to be earned.  
And then you have to be careful not to lose it."*



# The Corner Stones of Family Collaboration with Loved Ones

KATRI HÄNNINEN



**From the very beginning, our work has been directed by the idea that when building good lives for people in need of special assistance, we must include the people close to them, their loved ones. The corner stones of our family collaboration have been smoothed out by years of collective development.**

**T**he roots of the Service Foundation for People with an Intellectual Disability (KVPS) are set deep within the field of families' support associations. The civic organisation Inclusion Finland KVTL founded KVPS in 1992 to develop and produce services not only for people who need special assistance but also for their loved ones – together with them. In 2007, the Service Foundation for People with an Intellectual Disability founded KVPS Tukena Oy to take charge of providing the services, and thus the KVPS Group was born.

Because of our roots, from the very beginning our work has been guided by the idea that in order to build good lives for people with special needs, we need to include the people closest to them, their loved ones. We have developed family collaboration in various ways during the years. The largest and most extensive development has been carried out in our project Family Collaboration: Supporting Good Quality of Life that started in 2010 and ultimately became part of our permanent operations. This development guarantees that family collaboration will be preserved and strengthened as part of the KVPS Group's operations.

The project that we called Family Collaboration: Supporting Good Quality of Life includes half-yearly gatherings for either regional or departmental family collaboration days. During these gatherings we receive and share both knowledge and experiences from the standpoint of the practices of family collaboration, such as the values that guide our work and autonomy. Between these gatherings, we undertake various developing tasks, which our clients and their loved ones often participate in – we have recently taken part in the Change Day -campaign and did Zumba together, had an open house evening where we met with each other, crafted praise cards, and wrote stories for the people closest to us.

Over the years and during this development project, we have come to a mutual understanding of what family collaboration means to us, how it is executed in practice, and why it should be solidified even more. The corner stones of KVPS Group's family collaboration have been smoothed out by personnel during the project's training days.

### **The Corner Stones of KVPS Group's Family Collaboration**

- 1.** The basis of our family collaboration are the needs and will of the person who requires special assistance.
- 2.** We respect everyone's life story and increase our understanding of it by means of family collaboration.



3. Trust, respect, and genuine listening are the cornerstones of our family collaboration.
4. In our opinion, loved ones are an asset, and we utilise them to the best of our abilities for the benefit of the person in need of special assistance.
5. Our interaction with loved ones is open and confidential.
6. We cooperate with loved ones as equals. We all have the shared goal of giving people with intellectual disabilities a good quality of life.

1. **The basis of our family collaboration are the needs and will of the person who requires special assistance.**

Our operation does not stem from the loved ones' or service providers' needs, instead we examine the needs and will of the person who requires special assistance together. The will and needs of this person determine how we act. The main purpose of our work is to help this person lead a good life.

2. **We respect everyone's life story and increase our understanding towards of it by means of family collaboration.**

Every one of us has a history that lives in us even though we grow and evolve. It cannot be dismissed but should be understood as experience and strength. When we cooperate with loved ones, we can better understand each person's history, hear stories about their past, childhood, and roots, which are important to all of us. Knowing a person's life story enables us to support the development of his or her identity as well as provide individually tailored services.

The loved ones themselves have their own stories. Sometimes those stories are full of sorrow and experiences they have not dealt with. As a service provider, it is important to understand that these types of things may have left their mark and may therefore affect the loved one's attitude. It is wise to take time to ask and listen to how the loved one is doing as well.

### **3. Trust, respect, and genuine listening are the cornerstones of our family collaboration.**

Family collaboration requires mutual trust. Trust is born out of listening and respecting the other party. Sometimes there are situations where the loved one's opinion must be contested, but by trusting and truly listening to each other you can still reach a successful end goal. The loved ones' wellbeing and trust towards the services affect the life of the people with intellectual disabilities and advance the staff's wellbeing, too.

Respect includes understanding the fact that loved one's are different from each other: some of them want to be actively involved in everyday life, while others are less likely to do so. Sometimes mundane reasons, such as health and life situations, prevent them from participating.

### **4. In our opinion, loved ones are an asset, and we utilise them to the best of our abilities for the benefit of the person in need of special assistance.**

Loved ones are a remarkable asset both for the person who needs special assistance and for staff members. It is crucial to create an open and respectful relationship with loved ones, so that their know-how may become visible and can be used to benefit the client. Loved ones can help during various events or outings. It is not wrong to ask for them to help. It is important to

maintain relationships, so that they do not disappear from the person's life during his or her lifetime. Loved ones often have the kind of knowledge and understanding that service providers can never obtain.

We cooperate with loved ones as equals. We all have the shared goal of giving people with intellectual disabilities a good quality of life.

It is vital that all matters may be discussed, and even difficult things can be brought up in conversation. This ensures the loved ones that they can trust the staff to truly take care of the person in need of special assistance instead of going through the motions to please them.

### **We cooperate as equals. Our goal is the same as the loved ones' goal: providing good quality of life for people with intellectual disabilities.**

We do not raise ourselves above the loved ones under the pretence of our professional skills. Instead, we cooperate equally, respecting one another and each other's expertise. Our common goal, ensuring that the person with an intellectual disability has a good quality of life, is best reached by working together as equals.

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#### **What is the KVPS group?**

In 2007, the Service Foundation for People with an Intellectual Disability founded KVPS Tukena Oy to take charge for providing the services, and thus the KVPS group was born.

# Service User's Good Quality of Life Is Supported by Active Family Collaboration

RAIJA HYVÖNEN AND MERJA SEPPÄNEN



**In the Kesäheinä Service Unit, cooperation between service users' loved ones and staff is based on common activities and shared experiences. Mutual trust and understanding stem from open communication.**

**"E**ager hands and focused faces reveal that something wonderful is about to take place. The mood is heightened by mothers, fathers, and other important people who have come to visit. The Kesäheinä and Ilmarinrinne Service Units' joint baking event is about to begin – today's programme includes baking bread and pasties. The baking oven has been warming up since morning, and it is waiting for the goods to be ready for baking. Which they will soon be, when everyone gets to make their own Karelian pasty or traditional rieska bread. The traditional recipes and baking heritage for the Karelian pasty, Kainuu rieska, and Savo rieska are passed down from generation to generation, when mothers teach the service users and staff the secrets of baking. Soon, we'll get to have a taste! In the hustle and bustle of everyday life these types of events solidify our common goal, providing good quality of life for the service users."

The Kesäheinä Service Unit has always executed family collaboration. It has not grown on its own and straightforwardly, instead it has had to be learned gradually, through experience.

Today, loved ones have an active and significant

role in everyday life at Kesäheinä. They support the service users in building and leading a life of their own making, and by offering concrete assistance they enable the service users' involvement in various events, such as concerts, outings, or sports competitions. Helping hands are always available at berry picking season; berries and juices are both brought and frozen together.

### **Solidarity and Trust Are Built Together**

The spirit of Kesäheinä is based on common history as well as shared successes and mishaps. There is already a yearly tradition where the staff edit a film of the highlights from the previous year. It showcases everyday life at Kesäheinä, starring the service users of the Service Unit. After the screening, the reminiscing continues at a potluck evening meal provided by the service users' loved ones.

The service unit's garden also offers things to do together. It has been crafted by the service users' parents ever since the building was completed. The garden hosts trees, bushes, flowers, strawberries, wall plants, swings, a fountain, and a grill gazebo. In other words, there are lots of spots to enjoy the four seasons. The garden is dear to the service users and their loved ones – it is beautiful, but more importantly, it has been done by hand. The perennials brought from the service users' childhood gardens tell stories to both the service users and the staff. Hearing these stories has tied

In Kesäheinä, mothers known for their delicious traditional rieska bread were invited to lead a workshop for service users, loved ones, and employees. Pictured above with their hands in flour are mother Anja and daughter Anna Pyykkönen. During baking day everyone enjoyed spending time and doing things together!

PHOTO: MERJA SEPPÄNEN



together service users, families, and staff.

*“Trust is born out of shared experiences, too. People grow to know each other through open communication, visits from loved ones, and encounters during everyday life.”*

The better the staff and the loved ones get to know each other, the easier it is for them to bring up things to discuss. In a confidential relationship, know-how and information is shared.

Building mutual understanding and shared knowledge begins as soon as a new service user moves into Kesäheinä. Appreciating the fact that the service user’s life story is present in every moment makes the person and their life individual. The information loved ones share about the life the service user has led previously supports the Kesäheinä staff to plan for the future together with the service user and the loved ones.

### **The Service Provider Knows the Service User and His or Her Loved Ones**

Having a designated service provider builds and maintains family collaboration that is based on trust. It rests on professionalism, which means that the rules of the relationship and their practical implementation is agreed upon with every family individually. A good example of differing practices is communication: some loved ones want to hear what is going on via text message or e-mail, while others ask for an occasional

phone call. Some families are fine with a more substantial update when visiting the service user. What matters is that things are done as has been agreed.

Supporting interaction is a valuable part of a service providers job. A service provider supports and represents the service user and brings forth his or her opinion in all everyday situations. Because people carry all kinds of things with them from their past, wishes, experiences, and values into all interactions, we must stop to listen what the other party means to say. This is best done when the service provider has enough time to get to know the service user and his or her loved ones.

**The Kesäheinä Service Unit** is a home built by the Service Foundation for People with an Intellectual Disability, where services are provided by KVPS Tukena Oy. The service unit, located in Kajaani, offers a home, around the clock service accommodation and daytime activities for twelve people with intellectual disabilities who need special assistance. The staff supports, guides, and assists the service users at all hours of the day, so that they can live in a home of their own.

# From an Institution to a Community Living: Challenges and Opportunities for Family Collaboration

KATRI HÄNNINEN



**A family member with an intellectual disability moving from an institution to a community is a change that causes feelings of uncertainty and fear in the loved ones' minds. The significance of family collaboration is highlighted when the home is in the vicinity of parents and siblings.**

**A** family member with an intellectual disability moving from an institution to a community is a change that causes feelings of uncertainty and fear in the loved ones' minds. The significance of family collaboration is highlighted when the home is in the vicinity of parents and siblings.

When I was asked to explain what family collaboration is like when working with a service user and loved ones during a move from an institution to community living, my first thought was that it is the same kind of family collaboration as in any other circumstance. The starting point is just a little different. After I stopped to think about the matter more closely, I did find some special features that I had noticed when working with people who have an intellectual disability and their loved ones who were all preparing for a move out of an institution.

For this article, I interviewed two mothers, who wanted to share their experience with family collaboration when their children moved from institutional care to community living, into their own homes in KVPS Tukena Oy's Lamminranta and Vuores service units.

Thank you, **Leena Lähteenkorva** and **Merja Tollet**, for sharing your lovely thoughts!

### **Fears and Insecurities**

One might think that when you have let go of your child once as they have moved from under your roof to an institution, having a child move from the institution to a home of their own would be easy – it could be compared to a move from one town to another. However, it is not always that simple.

In the loved ones' get-togethers for the One of the Neighbours -project\*, we had extensive discussions concerning the feelings and emotions we had about taking down the institutions. Most loved ones said that they were afraid that the security the institution had brought would crumble and the responsibility and care for the person who was moving would be shifted back to the parents or other loved ones. In the moving training one mother was afraid of ripping open old wounds:

*Handing a child off to an institution was so painful at*

\* One of the Neighbours – Deinstitutionalisation in Finland (2011–2014) was a project conducted by the Service Foundation for People with an Intellectual Disability (KVPS) based on the Finnish government's resolution to decrease institutional care and creating new forms of housing. The leading idea was that no one is too disabled to live in a home of their own.

*the time that she did not want to live through those same emotions again when her adult child was moving away from the institution.*

Fears were alleviated by common discussion. The atmosphere of get-togethers became very trusting and supportive towards closing the institutions. The mother who had feared ripping open old wounds participated in the moving training time and time again, and was happily supportive towards her child's move, while gaining strength from the other parents.

### **Elina Moved from an Institution to Lamminranta Service Unit**

**Elina Lähteenkorva**, daughter of Leena Lähteenkorva, moved to Lamminranta service unit in Forssa as soon as the home was finished. Everything was new: new home, new staff, and new neighbours. There was plenty of uncertainty as to how the family's "sweetheart" would be cared for. Elina had lived in an institution for seven years.

When Elina had moved to the institution, Leena felt like her daughter had been taken into custody. The loved ones did get a say in things, but the institution's practices were set and the idea of loved ones walking Elina through the moving process and escorting her into her new life had been missing.

As Elina settled into Lamminranta, all fear for the future was erased very quickly – Elina was obviously doing great, which made the loved ones

trust the staff. Before the move, Elina's loved ones and the staff had discussed the important things that gave rhythm to Elina's life, such as sleeping, eating, postural care, and her reactions to various things. Loved ones had been listened to and heard. The director of the new home visited Elina's childhood home and got to know Elina's loved ones and her life story. No wish was too small to be respected, and the staff understood the value these wishes had to Elina's life.

### **Moving to a Home Brought Loved Ones Closer**

When **Jan-Erik Tollet** moved to Vuores service unit, he also moved closer to his mother Merja and his siblings. Merja rejoiced over his move, because that meant that all her children would live within a walking distance from her and each other. When Jan-Erik still lived in an institution, the journey to visit him was long and trips had to be planned well in advance.

– Now I can just stop by quickly. The time we spend together increased by at least 90 per cent, says Merja Tollet.

The shorter distance is not the only reason why they are spending more time together, however. In Vuores, the staff regards family collaboration valuable, and Merja always feels welcome to visit.

– It's like coming home. The doors are open and there are no thresholds, she states.

Jan-Erik now gets visits not only from his mother,



but from other relatives as well. He has organised a birthday party at his own place, and all his close relatives were in attendance. Merja has grown closer not only to her own son, but to other service users, too, and sometimes Jan-Erik has even seemed jealous of her.

Leena also feels welcome to visit Elina. Lamminranta hosts mothers' evening coffee hours, which have already become quite the tradition, and during which it is possible to talk and get support from other loved ones. Sometimes these get-togethers include the whole gang, as staff and service users join in.

Even though Elina and Jan-Erik have both moved closer to their loved ones, the responsibility of their care has not been shoved onto their mothers' shoulders.

– We have the opportunity, not the obligation, to take care of things, says Leena. Elina has lived in the service unit for five years, and the managers now have responsibility for her clothes and décor, too – Leena can focus on being Elina's mother.

The situation has not always been as bright as it is with Elina and Jan-Erik. Long periods of institutionalisation have severed ties with loved ones, and now there is nobody to greet service users arriving in their new home. Luckily, most of these situations have turned out for the better: after moving, some service users have found relatives nobody even knew existed.

Often people find it less intimidating to visit a service unit than an institution, which may, for example, stir sad memories in siblings. This ease of visiting a service unit has brought many siblings closer together.

Moving into community living may also facilitate new friendships – a loved one may not always be a relative. Loved ones may be found in other close circles, too.

*In order to be able to support valuable relationships, the staff must be active and understanding towards the meaning of social interactions and family collaboration.*

### **Appreciation, Trust, and Mutual Understanding**

– If I ask, people answer me and explain things openly. This was not the case previously, explains Merja and praises the communication between loved ones and the staff at Vuores. The staff values the loved ones' expertise and asks them for advice and tips on what to do with the service users.

*Appreciation for loved ones may be seen in the way things are done together as equals – the staff does not raise themselves above the loved ones under the pretence of their professional skills.*

Cooperation includes respect for others and common work towards a shared goal: giving the service users a good quality of life.



Leena highlights the significance of conversation and mutual understanding. The conversation is tinted by the experience of her child living away from his childhood home in an institution. Emotions may surface more easily, as may prejudices and assumptions.

– The trust that has been born little by little has opened the conversation. Loved ones have the right to admit that they're tired and angry. After talking it through, their stance may change, Leena admits.

According to Leena and Merja, successful family collaboration requires participation from loved ones. It is based on trust and mutual respect. The staff build trust by being open and discussing matters with loved ones.

### **Access to Loved Ones Reduces Challenging Behaviour**

Brian McClean, leading psychologist of the Irish Brothers of Charity, has done excessive research on people who end up in challenging situation and the reasons behind challenging behaviour. He has concluded that the people who end up in challenging situations have often lost their home and all connection to their loved ones.

Olavi Hietaharju, a previous chair of Me Itse ry (We for ourselves), has stated that "Everyone has a reason for their rage. Nobody is angry without cause. There is always a reason for feeling bad, and nobody rants and raves deliberately". Maybe this rage that Olavi describes here, being put in a challenging situation without wanting to, is evidence of the fact that people long to have access to their family and other loved ones.

According to Brian McClean's research, building relationships with family has radically decreased challenging behaviour. Four out of five of the participants in the research project ceased their challenging behaviour within a year of reconnecting with their families. This, if anything, suggests that family and loved ones have an immense positive effect. It is therefore vital to strengthen family collaboration and for staff members to work towards creating meaningful relationships to those, who do not have loved ones in their lives.

# Cooperating Closely and Openly with Loved Ones Supports Independence and Good Quality of Life

ELINA LEINONEN



**The Pehu family consists of mother Pirjo, father Sakari, and adult children Tiina and Kalle. When the children were small, they still lead an ordinary family life. As Tiina and Kalle grew, however, the family faced new challenges, because both children were diagnosed with a chromosome disorder that caused intellectual disability.**

**T**iina has always needed plenty of help and support in her day to day life, but she was always the sort of child who has special needs but who is very satisfied with her life. Instead of using recognisable words, Tiina expresses her emotions by smiling and vocalisations.

Kalle, on the other hand, has been an alert young man ever since he was little, and has whizzed around town on his bicycle and had adventures on buses across the Pirkanmaa region. He finds it easy to get to know new people and has accumulated many friends and acquaintances along the way.

### **Rest Is Important for Family Caregivers**

For 30 years, Pirjo Pehu has led the everyday life of a family caregiver, and continues to do so, because Tiina still lives at home with her parents. Pirjo has a bright outlook on life; she finds much joy in her children and is pleased with the services she has received.

– Our home municipality has understood the importance of supporting the family caregiver, and I have had breathers when I have needed them, states Pirjo Pehu. In her opinion, Lempäälä has been a great place to live with children who have special needs.

Tiina has been granted short-term care during the weekend every three weeks or so. The Tulppaanikoti home in Tampere has offered a familiar and safe place to stay. The municipality has also paid for one summer camp for Tiina every summer.

– These short-term care periods give me a chance to take a breather, live on my own terms, to go where I please or not go anywhere at all. They also offer Tiina recreation and a change of pace, Pirjo Pehu says.

### **Dreams of Independence**

Seven years ago, Kalle Pehu moved into his own home in the then newly finished Pesäpuu service unit in the centre of Lempäälä. When this new unit was in the planning stages, Kalle immediately informed everyone that he wanted to move there.

– Kalle's strive for independence was easy for us parents, because he himself was so ready to move into a home of his own, remarks Pirjo Pehu. As a mother, she is pleased that she has allowed her son to move around town and gain independence ever since he was little, even though it frightened the parents occasionally.



Settling in at Pesäpuu was extremely easy. Kalle began calling his place his number one home, his bachelor's chamber, and his childhood home his number two home. Nowadays Kalle rides his bicycle to his parents place almost every day to eat or bathe in the sauna, to help with mowing the lawn or shovelling snow.

– I do wonder about the future, because Kalle is still so tightly attached to me. He doesn't want to think about me growing older and becomes anxious at the very thought of it. It is sad to think about how he'll manage to move on when his mother is no longer with him, Pirjo Pehu says.

– Tiina also has one foot out the door. Us parents may develop the so-called "empty nest syndrome" when she moves out of her childhood home, laughs Pirjo Pehu. Tiina moving out is a dream her mother hopes will come true when more apartments for people with special needs are built in their home municipality, if not before then.

### **Open and Smooth Family Collaboration**

Pirjo Pehu feels that both Pesäpuu and Tulppaanikoti service units show open and smooth cooperation

As a mother, Pirjo Pehu hopes for respect and the ability listen from the staff who works with her children, Kalle and Tiina.



between staff and the service users' loved ones.

– We call and text each other about good and bad stuff alike. I hope that the staff can talk directly to me about things they find difficult as well, states Pirjo Pehu.

– I've asked to be contacted if there are any problems. As the mother I might have tried and tested methods to solve them. No issue is too small for the staff to call me and ask, Pirjo Pehu emphasises.

*"It is good to respect the knowledge and experience of the parents."*

Pirjo Pehu deems it important that loved ones and staff can have open conversations and cooperate in good spirits to solve the problems that occur when service users gain more independence and live a life of their own making. For example, at Pesäpuu, Pirjo and the staff have had conversations about where to draw the line between respecting Kalle's autonomy and limiting the time he spends playing computer games late at night. Kalle would like to stay up late, which often causes him to be tired during the day.

*"It is important that loved ones and the staff can solve everyday life issues together."*

In Pirjo Pehu's opinion, there are many ways in which loved ones can participate in supporting the service users' good quality of life. She herself is an active

member of the Pesäpuu volunteers alongside three other families. These volunteers have helped in various events, such as the "Olympic Games" taxi drivers organised in the service unit's yard. They have also participated in boating days, organised by Lempäälä boaters and the services for people with disabilities, by preparing sausages and pancakes.

### **Dreaming of Care Work as a Profession**

*"I hope the service users are respected and listened to, and that their autonomy is respected as well."*

Pirjo Pehu lists things she especially hopes for from the staff who work with Tiina and Kalle. These are the values she will also be able to implement in her own work in the future.

On top of being a family caregiver and an active volunteer, Pirjo Pehu is studying to become a care assistant for people with disabilities. Her dream is to begin a new line of work and new phase of life once Tiina has moved out.

Pirjo Pehu has a deep love for children with intellectual disabilities and care work.

# The Life of One Brother and Two Sisters – Together and Apart

SIRKKA NIKULAINEN AND LEENA NUUTILA



**When siblings have a close-knit relationship with each other, that relationship can carry an entire life. Common history, shared experiences, and deep trust build a friendship that lasts a lifetime. Us two sisters decided to gather together our own experiences as siblings.**

Siblings may find similarities between families, such as the number of children, age gaps, the roles of the first born, middle child and youngest, as well as the development changes of childhood and puberty. Still, every family is a unique community with its own story, and all siblings have their own personalities, characteristics, and memories.

When a brother or a sister has an intellectual disability, it affects the other siblings' choices, identity, values, and attitudes.

Growing up alongside a sibling who has special needs comes with an assortment of situations and emotions that siblings must face and address, and that children, who live in families without disabilities, do not need to think about until much later in life. These emotions include responsibility, a thirst for knowledge, a need to protect, standing up for what is right, acknowledging other people, and acceptance towards others. Nevertheless, we all experience the joys and happiness that are a part of life, too.

At their best, sisters and brothers who need special assistance bring a richness into the family, which tints the other siblings' actions in a distinct

manner. Often, the value of a sibling with special needs and the significance of all the experiences you share can only be understood in adulthood. This happened to the siblings in our family, because the "special-baby" we shared a childhood home with has had significant influence on our lives, the values that guide our actions, and our career choices. Nowadays both of us sisters have extensive experience from special education as well as social services and services for the intellectually disabled.

### **Sisters and Their Brother**

Us sisters are bound together by our little brother, who is well over 40 years old. This may give you an idea of the fact that we big sisters are no "spring chickens" either. We have decades of partially shared life behind us. The more times we have travelled around the sun, the less our brother's intellectual disability matters in our mutual interactions. We know each other's characteristics and the ways each of us acts. Recognising each other's personalities produces humorous and funny situations when we spend time together. As an example of this is how our brother Mikko blows us away with his quick wit and amusing one-liners: "*Sisters are being silly again!*"

Our brother is not only funny and in possession of a great sense of humour, but also polite, empathic, and kind. He is a gentleman who takes others into consideration and is almost always in a good mood.

If he ever has any wishes, we get to hear them very discreetly presented: *"I must confess that my hunger is still lingering just a little bit... Could it be time for tea now, could it?"*

For the past few decades, we have spent short holidays together. For us that means the occasional weekend here and there, whereas bigger holidays are always intertwined with Christmas, Easter, and the summer. Bank holidays and birthdays set the pace for our relatively tight communication, because spending them together is an important tradition from our childhood. Usually our gatherings are coloured by us all letting loose and joking around – each of us has the space to relax and be themselves. Songs resound from the sauna benches, because Mikko is an avid sauna-goer. These songs are funny, because their words are made up on the spot, spontaneously, to fit the situation. We spend our evenings restfully watching films together; most often our favourites are the James Bond films. This is when you can hear nervous comments from the sofa: *"That fellow is all silly... I wonder how this is going to go?"* or *"Now it went over the hedge! That fellow got booted into the jailhouse! This is very bad going!"* The three of us also love shopping, and sometimes, when the we get the chance, to go to concerts or the theatre.

One of us sisters has a family of her own with two adult boys. We sometimes visit them and have a jolly old time. If the young lads start to joke around about something with Mikko, by return mail they get

statements like: *"I'll put hornets and bees onto your neck! How would you like that?"* or *"Don't you play with fire! I'll stick icicles into your shirt!"* Mikko is also godfather to one of the young men, which has been an important role for him. This chain of godparents has been and continues to be valuable to us, because we have had Mikko's own godparents with us ever since childhood. They are loved by all of us siblings. The people around us who remember our roots have become an important network of loved ones for Mikko.

### **Those Were the Days...**

As we reminisce with our brother, we remember situations from our childhood and youth when we siblings used to play and sing. We taught our little brother to talk, walk, and participate in daily activities. We rejoiced when we noticed Mikko learning lots of things. In our family, it was only natural that we sisters cared for our baby brother. We did so gladly and eagerly, even though we worried about him from time to time. Feeding our little brother or teaching him a new skill called for special know-how from us sisters. Gradually, we sisters also learned many useful skills by doing things together. Our mutual perseverance paid off, because we felt joy in our achievements and had reasons for happiness that solidified our relationship.

The experiences of our childhood and youth cultivated patience, independence, courage, and

initiative in us. Little by little we learned to take and share responsibility, which has benefited us later in life. We also learned to face difficult situations, such as when we had to answer other people's questions about Mikko's disability.

*When we were fairly young, we had to process emotions that arise when encountering difference, emotions that other people our age have said they have had to deal with much later in life.*

### **Knowledge and Openness Help to Understand Emotions**

In our childhood, we had regular home visits from a rehabilitation instructor, who acknowledged us sisters in guiding Mikko. This instructor was a welcome visitor, who became important and close to our entire family. When the instructor taught Mikko to communicate using pictures, for example, they encouraged us sisters to utilise the pictures to support our communication. It was vital to know what the methods used with our brother were and why they were used. As knowledge was joined with seeing, doing, and experiencing, we gained better understanding our brother's situation. Participating in the rehabilitation helped us see Mikko's personality and the traits that were linked to his disability. Gradually this realisation impacted us so that Mikko's presence in all activities was extremely normal.

We had enough information about our brother's

disability very early on. Realistic information about the opportunities and limits of his development and learning aided us in understanding Mikko's speciality and its significance. Having the right kind of information alleviated feelings of powerlessness or guilt, for instance, lessened our helplessness, and set the right proportions to what it meant to manage in various situations. Experiential knowledge gave us a great base from which we could look forward to the future.

### **The Steps into Adulthood**

As a teenager, our brother amusingly remarked that he was celebrating his "youth festivities". It was a good sign of stepping into adulthood. Everyone is entitled to building a life of their own, breaking free from their childhood home, and gaining independence. For us, it was especially important to see Mikko as a slowly maturing brother, not a "perpetual child", which was what other people often called him. Even though we lived in different municipalities and sometimes very far from each other, our interaction never ceased.

During the courses of our lives we have had phases that follow one another, together and apart. The present has been built from history, and the future from the present. We feel that the childhood we spent together has painted a lasting picture of what it means to be siblings. Our lives have, of course, included many challenges and turning points, but knowledge, trust,

and our close-knit relationship have helped us move past them. By growing up and becoming independent, each one of us has been shaped as a human being, but the partially shared chain of life has kept its meaning and strength.

As more mature adults we assessed our future, which helped us to consider our parents' aging. It seemed very natural, then, for one of us sisters to become Mikko's official trustee. We felt that it was positive thing to have a trustee in the background who knew not only his wallet but him as a person. Knowing what kind of support and services are available and what they cost makes it easier on us to plan a life that is in Mikko's best interests. Sometimes this official status creates credibility when dealing with bureaucratic issues. It has brought clarity to the cooperation between various parties around Mikko.

We feel that it is important to get to know, respect, and truly listen to the everyday life of the community your loved one belongs to. Presenting ideas and questions openly, receiving information or simply catching up have added to the mutual understanding we have among staff, Mikko, and us sisters. Cooperating, setting goals, and adjusting our wishes to fit into appropriate proportions may all be successful if we can set ourselves in the place of our cooperation partners. The most important factor between us is the fact that we are siblings, because the other more official roles only affect in the background as added value. These parts have built

the courage to trust all parties.

### **Siblings in Old and New Ways**

Reacquainting with your siblings as adults may be interesting and meaningful. As we now, as adults, live separately, the way we siblings meet each other and take each other into account have a different kind of weight than they did when we were children.

Our shared history is a great breeding ground for individual development, independence, and detachment from each other, but it also unifies us in a lasting manner throughout our lives.

As adults at the latest we have the valuable opportunity to see and hear, what type of people our sisters or brothers truly are. Luckily, we can knowingly create common points of contact in our lives. Siblings who are very different from one another can find common ground by openly caring and being interested in our siblings' everyday lives, interests, work or family. Siblings ought to give each other the opportunity to talk about their own lives and themselves. Gathering together and listening to your siblings calmly may help you to see something old in a completely new way.

### **Drops of Joy on a Small Vacation**

On a fading autumn day, an ambient cluster of candles are burning on one sister's kitchen table. Coffee tastes especially good right now, since the vacuum cleaner

has been humming during the day. The brother is on his way to eagerly spend a small vacation with his sisters. This time it is going to be a long weekend. The other sister is arriving from Hämeenlinna with time to spare, which means that the scent of fresh bakes is going to fill the air. Maybe we will whip up some Christmas pies, play some Christmas music, and go Christmas shopping – we are all “*Christmas fans*”, after all.

Oh! The other sister seems to have just driven her car to the parking space in the yard, and soon the brother will arrive as well. This is where our small vacation begins – this is where small, commonplace, and simple drops of joy begin!

### **The Ten Commandments of Siblings**

- Stop and think about who your brother or sister truly is: What do they like, what do they not; what do they want; and what do they dream about.
- Listen to him or her. Instead of talking about your own stuff or leading the conversation into things you are interested in, listen to what your sibling has to say.
- Offer to help when your sibling needs it.
- Do not push or give advice but show your sibling that you’re available if needed.



- Talk about things that are on your mind.
- Accept help and support, too.
- Be brave enough to show your vulnerability and to accept help, even if you’re the older sibling.
- Open the window to the near and distant future, because it is coming for all of us.
- Reminisce on good times from your childhood.
- Give space for your sibling’s personality. Enjoy your own ideas and theirs.
- Allow time for yourself and for the development of your relationship as siblings. Take time for these things even in the middle of everyday life.
- Ask how your sibling is doing. Remember to show that you care.
- Have fun and enjoy your time together.





# Cornerstones of Close Cooperation

From the very beginning, our work has been guided by the thought that when building a good life for people with special support needs, we need to include the people closest to them, their loved ones.

Cooperation with loved ones is one of the basic pillars of our work. The loved ones and we have a shared objective; giving people with disabilities the opportunity to lead a life that is independent and of their own choosing.

This book, 'Cornerstones of Close Cooperation', is a collection of thoughts and views regarding open and trust-based cooperation, with which staff members and loved ones may contribute to good everyday life in service units and work and daytime activities. The cornerstones of our close cooperation have been smoothed by years of joint development work. This book provides a voice for the experts of close cooperation: mothers, fathers, and siblings.

