Silmäterä

The Apple of My Eye

SPECIAL EDITION 2012

We are Incredibly Lucky

The Girl from a Sheep Farm

In This Issue

Editorial Our Story

4 We are Incredibly Lucky
Leo introduced joy and energy in the Immonen family.

8 Association
From the chair: A medal to the parents
Association for Parents of Children with Visual Impairments
Memories of summer 2011

13 Reimakka
Special parenthood of a special child.

14 A Day at a Time
Life carries over difficulties.

16 Hattifatteners are Particularly Special
Visiting an integrated special day care group.

19 The Girl from a Sheep Farm
Rheumatism, blindness, and life at a sheep farm – Toivola family's full life.

22 Possibility for Play and Interaction
The physiotherapy of a multiply disabled child progresses in small steps.

24 Lassi's School
The Variska School in Vaasa prepared carefully to welcome a visually impaired pupil.

27 Ronja
Change in life with gas.

28 Medina's Good Life
Medina Omeragic is a 16-year-old schoolgirl who moved to Finland from Bosnia.

30 Therapy on Horseback
Santtu Aaltonen goes to riding therapy.

33 What You Hear on the Streets
In a cross-modal environment one can also manage when blind.

35 Service Form

Back cover Peer Support – an Opportunity Worth Taking

Silmäterä
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Our Story

It was the year 1970. Eighteen parents of children with visual impairments gathered in Tuusula, near Helsinki, to found their own association: an association for parents of children with visual impairments. A period of active operation followed the establishment of the new association. The parents organized summer camps with no hired workers. Certainly, none of the founding members could have imagined how big the association and its operation would grow during the next forty years.

The world was much smaller in those days; one rarely travelled abroad, and not too many people from outside the country had settled in Finland. Yet the first active members also directed their attention outside the borders of Finland. They made trips to Sweden and Denmark, where they familiarised themselves with the local schools for the visually impaired.

It is a giant step from those days to the 2010s, when we have numerous immigrant families amongst us, or families with one of the spouses originally from somewhere else. There are also families who live and work outside Finland. This gave us the incentive to make our first special English edition of the Silmäterä magazine.

Silmäterä is the member magazine of the Children with Visual Impairments Association, which tells about the life of a child or young person with a visual impairment and his or her family. The word Silmäterä has two meanings in Finnish. On one hand, it means the middle part of the eye, the pupil, and on the other hand, a child who is very dear - in English the second meaning would be “the apple of my eye”.

A regular Finnish language Silmäterä issue publishes the stories of families, as well as plenty of information about social security topics, and notifications of events, which have both been left out of this issue. This issue primarily describes life in Finland through the experiences of families of children of different ages with different visual impairments, or visually impaired and multiply disabled children.

We would like to thank those who have made their own story public to provide peer support to others. I hope that this special issue reaches many such families we cannot reach in Finnish.

Leena Honkanen
Executive Manager

ANNE LATVA-NIKKOLA

PHOTOS: LEENA HONKANEN

■ For the Immonen family the worries are now history. The everyday life of the family is full of bustle and activities.

Text **Leena Honkanen** *Published in Silmäterä 2/2010*

We are Incredibly Lucky

Leo Immonen is a 2-year-old boy, blind from birth, who had more than an average share of hardships during the first weeks of his life. Two years have changed the worries to joy; the Immonen family glows with happiness because of Leo and the little one who will be born in May.

When Leo was born, all was well at first, but his blood sugar began to decrease suddenly. The boy was moved to an intensive care unit for children. There were severe problems with his glucose production and medication was started when the baby was only a week old. At the age of two weeks it was noticed that there might also be something wrong with Leo's eyes. The eyes were examined when he was two months old, and as a result, a preliminary visual impairment diagnosis was made. The final diagnosis was received at the age of five months: the boy had septo-optic dysplasia and the degree of visual disability was defined to be 100%. As young parents, **Tiia** and **Tomi Immonen** had to face a grave situation.

"Actually, after the initial adjustment, everything has only been positive," says Tomi Immonen. "Many things have gone much better than we first expected, and there's also been luck. One stroke of luck was the nominated nurse Leo was assigned to in the intensive care unit, Anki, whose observations quickly led to correct conclusions about the reasons behind Leo's problems, so the medication could be started at an early stage. Only the visual impairment proving to be so difficult felt bad at first, but we decided to accept that as a challenge, as well."

"Naturally, I would give anything for Leo to have his sight, but on the other hand, if he were able to see, he wouldn't be our Leo, who we are so happy and proud of. Leo is perfect just the way he is," says Tomi Immonen. "Moving forward and survival start when one embraces the facts."

Confusion and prejudice

The birth of a disabled child in a family also requires adjustment from relatives and friends. The Immonen family also had to face the fact that for some the child's disability was a hard thing to digest.

"The hardest thing at first was that when you were in need of support yourself, you then had to support others. Many of our friends could not accept Leo's blindness. "Someday the science will be able..." type of talk hurt, when you knew that there was nothing that could be done about Leo's blindness. You had already accepted the facts when others still had a need to maintain a vague hope."

"Some were even prejudiced. They seemed to think that because Leo is blind, something else must be wrong, too, and all our future children would also be disabled

in some way. The fact that people avoided using words related to seeing when in our company also hurt. They could not function and behave naturally with Leo like with those who could see."

"When you are already fine with the blindness, you get tired of only talking about the disability and being disabled. After all, Leo is a normal little boy who is fully entitled to have a happy childhood," says Tiia Immonen. "The parents of a disabled child want exactly the same things as parents of other children: that their own child would be invited out to play and sometimes to a sleepover, in all, a normal approach.

Household chores under control

In the Immonen family childcare is divided so that father and mother work different shifts. That way one of the parents is always at home with Leo. The result is that all household work is done while taking care of Leo and with him. And so the boy is already a skilful helper at home. For example, he can already use a washing machine and a dishwasher, as well as an electric mixer, and is learning to make coffee.

LEENA HONKANEN

"It would be nice to always keep the house clean, but there will inevitably be a mess when Leo bakes a cake or measures coffee. But the most important thing is that Leo can experiment and experience different things as much as he wants. Few families bake as many cakes as we do," laughs Tiia Immonen.

"Leo has a very inquisitive and bold nature. Everything needs to be studied and touched. That is why shopping, for example, can be quite an ordeal, because Leo would like to walk around independently there as well, and cannot understand why he is not allowed to do this. Whenever Leo has the opportunity to move around freely, we avoid all sorts of overprotection. Leo can climb on the sofa and jump on the bed all he likes. At the same time, almost without noticing, his balance and body coordination develop.

It is important to talk a lot with a visually impaired child, so that different phenomena in the world become familiar, even if the child does not see them. "Watching TV is part of life in our family, the same as in other families. I audio describe nature documents to Leo. Last time we watched a documentary about the life of an elephant and an eagle," tells Tomi Immonen.

Information is the key forward

When a child's disability is a new thing, the family must have access to information about support, services, and rehabilitation opportunities. Many terms and concepts related to services for the disabled may first sound really foreign. The Immonens came across the problem of not finding such a person in the service jungle who would have been able to guide them forward.

"Leo received good care in the hospital, but we did not get information about social security or rehabilitation, for instance. We had to look everything up and ask around ourselves. Luckily we knew enough to apply for a baby course organized by the Finnish Federation of the Visually Impaired when Leo was 10 months old," tells Tiia Immonen.

Leo has been blessed with the character and courage of an adventurer.

"At the course Leo was for the first time perceived as a child with a visual impairment. It was a new experience for us parents. The course provided us with such information about visual impairment that we would have wanted a lot earlier. It helped us understand the impact of blindness on development and guide Leo ourselves in everyday life at home."

"Leo's physiotherapist **Tuula Hirvonen** has also been of tremendous help. To Leo, physiotherapy is a pleasing game and adventure – an exciting world of doing and experiencing new things. It was amazing how quickly Leo's motor development began after starting physiotherapy."

"We also encountered the lack of information when we started to think about putting Leo in day care. We were told that it is not possible to put a visually impaired

child of under two year in day care, which, of course, was not true. It could already be the right time for Leo to get to play with children of his own age. Now that we are expecting another child, the day care issue will be solved automatically for the duration of my maternity leave, but the so called rehabilitating day care could soon be beneficial for Leo's social development.

Leo tours the world on film

Participating in the baby course a little over a year ago also made Leo a film star. **Kirsti Hänninen**, Rehabilitation Instructor, noticed that Leo was fine with even lively goings-on and trustingly took contact with an adult. Therefore, he could be a suitable co-operation partner in an educational film which instructs parents on how to handle a blind infant at home.

Kirsti Hänninen had made a similar film about her daughter Riikka in the 80s. The "Riikka video" had been actively used for rehabilitation purposes for almost 30 years. Hänninen felt that now was the time to update the knowledge and competence that had accumulated over her long career and life.

The dvd "Leo learns by doing" was completed in autumn 2009, and it has been shown to parents and professionals in several countries, even as far away as in the United States and China. The Immonens are glad that Leo can for his part tell the parents of other visually impaired children how great and busy life can be in spite of blindness.

"I would have been much more confident about the future had I seen such a film when Leo was small," says Tomi Immonen. I could really have used some encouragement back then. Now it just feels like Leo has introduced immense happiness.

Leo Learns by Doing

When a blind child is born into a family, the situation is new and confusing. The parents have thousands of questions but very few answers.

DVD about the everyday handling of a blind baby :

- How am I able to do everything possible for my child?
- How can our everyday life become ordinary, good and safe, yet active?
- How are thousends of repetitions possible?
- How to best support my child: am I overprotective or encouraging as a parent?
- How will my blind child get as many experiences as the seeing child?"

These questions are answered in this dvd *Leo Learns by Doing* about the everyday handling of a blind baby.

The tips on this dvd about the handling of a blind child suit most parents with an infant, therapists and those involved with the family. The information given also supports parent-child interaction. The dvd's length is 17 minutes. Price 25 € (incl. VAT) + packing and postage

In Finland to order the dvd, contact: Finnish Federation of the Visually Impaired Children's Rehab, tel. +358 9 396 041, anne.tiljander@nkl.fi +358 9 3960 4571

If the purchase is made by a company within EU, please include VAT number.

You can also order the dvd online www.good.lite.com/leo. Sound track also in Chinese and Spanish.

Leo Learns by Doing

The dvd *Leo Learns by Doing* is a helpful tool for anyone who interacts with a vision impaired child. Parents, caregivers, relatives, teachers, doctors, and any other person who would like to contribute to the connections with a vision impaired child will find this information valuable. This video tells a story about a vision impaired child named Leo, and his parents, who visit with his vision teacher. The vision teacher shares step-by-step techniques with Leo's parents to help Leo develop and strengthen his nonvisual senses and skills.

Though the award-winning video is a short 17 minutes, the positive impact it can make will be everlasting. Caring for and providing optimistic feedback to a vision impaired infant or child can be challenging. A vision impaired child will need to interact with their surrounding environment differently than a fully sighted child. Techniques are available to help build and refine the nonvisual senses and skills in a child with vision impairment as they start to develop from infancy to early toddler years. Early intervention is imperative to successful development and growing in a vision impaired child.

Leo Learns by Doing, from the Finnish Federation of the Visually Impaired, Finland, won a Silver Award in the 2011 WorldMediaFestival in Germany. The Silver Award was in the Training: Motivation category. WorldMediaFestival is a global competition for modern media founded in 2000 as an initiative by intermedia to honor and celebrate solutions in corporate film, television, web, and print productions on an international scale.

A Medal for Parents

Before Independence Day the President of the Republic awards various medals to people who have exceled in different areas. I am not saying that they have not earned the recognition; kudos to them for their significant work. I want to acknowledge and award a "medal" to all the parents of visually impaired children. You do valuable work for the benefit of your children. I will also include the professionals who provide their competence to improve the well-being of our children to the list of the ones to be decorated. I will not list every party separately – I wouldn't want to forget one of the many – a big thank you to you, there are many of you and you do a lot.

What are the grounds for granting the medal; here are a few:

FOR FILLING IN numerous applications. I have never counted how many forms and pieces of paper a caregiver of a visually impaired child fills in during the first 16 years; there are plenty: disability allowance application; disabled parking permit, Kela course applications, service plan for the disabled, family caregiver application, car tax refund application, rehabilitation grant application, travel bill applications, adaptation training courses, free-time assistant, facilities, alteration work application for residence, special care grant application, a vocational rehabilitation grant for a young person, subsidies available from different foundations for the visually impaired, (appealable) appeals and supplements to applications. Quite a jungle to clear!

ROUND-THE-CLOCK WORK DONE without counting the working hours. Many visually impaired persons are also multiply disabled, and thus the amount of work is manifold compared to a child with no disability. In addition, you have to take care of the other "routine" obligations properly: the other children of the family, work, hobbies, chores, shopping, cleaning, positions of trust, obligations of a good citizen (whatever they happen to be). There are hardly any days off – luckily there are some camps and courses during a year.

FOR PROMOTING CHILDREN'S rights. The society has created the framework for acts and regulations, where a visually impaired child and their family receive different services to diminish the gap with other children, what being disabled brings along. Very few of these services are readily available; no, before the doors will open the parent must be active and have stamina. Competent people await our children, as long as the parents know the route to the correct doors.

FOR PROVIDING LOVE, compassion, care, learning, warmth, encouragement, safety, guidance, skills, self-respect, and tools for life to the child. With these building materials a small valuable child grows into an older child who feels themself valuable.

FOR SHARING YOUR story with other parents. You being able to cope and your example has encouraged someone else, who has been taking the first steps together on the road with a visually impaired child.

FOR TAKING CARE of yourself. Without you the child wouldn't know how and couldn't.

You cannot wear the medal you just received around your neck, or on your lapel. Place it in your heart as an acknowledgment for the valuable work you do every day. Let it reflect on you from your child.

I wish you a great end of the year – there's still time to honour that New Year's resolution. In the end some wise words about Christmas presents, uttered by two 6-year-old Lapua boys: "There are too many presents if you don't know where to hide them."

Markku Alahäivälä

LEENA HONKANEN

Näkövammaiset lapset ry
The Association for Parents of Visually Impaired Children

Childhood, Parenting, Peer Support

The founding meeting of the Finnish Association for Parents of Children with Visual Impairments was held on 11 June 1970 by 18 mothers and fathers who had realised the importance of sharing experiences and working together to promote their children's interests. These parents' energy and dedication carried the Association forward to what is now a community of more than 700 members, with families of children who have low vision, are blind or have multiple disabilities from all over Finland involved in the activities.

ANNE LATVA-NIKKOLA

Activities

Family meetings and regional events are the first step into the Association for many families, providing them with the opportunity to meet other families in similar situations.

Camps, courses and national weekend events bring a welcome change to everyday routines. Camp activities include games, adventures, swimming and campfires. Doing things together helps children with visual impairments make friends with their peers.

Be with me! clubs are special clubs for 8–13-year-olds with visual impairments, with *Be with me!* summer camps also available for this age group.

Information

The Association's member magazine, Silmäterä, was originally a camp newsletter published by volunteers. Today Silmäterä is published in four issues a year and is full of information about parenting, rehabilitation, social security, day care, schooling – everything relevant to the lives of our member families. These days the Silmäterä magazine is also complemented by the silmatera.fi website.

Advocacy

The Association is a member of many associations in the field of social welfare and health as well as the Finnish Federation of the Visually Impaired (FFVI), advocating the rights of visually impaired children and their parents in cooperation with them.

Funding

The Association is primarily funded by Finland's Slot Machine Association (RAY), with donations also received from private persons and organisations.

"It's often impossible for outsiders to understand how important the family meetings are. So many of us benefit from being able to tell others about our situations and be understood by those listening. It's such a relief to realise that it's OK to have these feelings in this situation. Hearing the stories of your peers is really comforting. The group allows you to share your experiences as a parent. This shared experience also generates resources that help you cope in the future."

(A mother's thoughts about the family meetings)

Finnish Association for Parents of Children with Visual Impairments

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RAY in brief

The main purpose of Finland's Slot Machine Association (RAY) is to raise funds through gaming operations to promote Finnish health and welfare.

RAY's gaming operations are based on offering entertaining and exciting games and services in a responsible manner. RAY's entire proceeds are used for supporting Finnish health and social welfare organisations as well as for the benefit of the country's war veterans. The aim is to continue to achieve excellent results in a highly responsible manner and thus secure funding for innumerable important projects and ventures.

Memories of Summer 2011

Regional camp of the capital region

In June families from the capital region spent a weekend on Villinki Island. The participants got to sail on the boat of a visually impaired skipper, Jukka Jokiniemi. The Villinki weekend is part of the regional activity of the Association for Parents of Children with Visual Impairments, organised with the help of voluntary peer supporters and families of the participants.

Be with me!

The Be with me! camp for tweens was held in Koivupuisto, Ylöjärvi in June. There were 7 girls and 4 boys. At the camp they exercised, played, did handicrafts, swam and enjoyed the sauna. The most important thing was, of course, good friends and nice instructors.

The Be with me! clubs for 8-13 year-old visually impaired children gather in different parts of Finland: Helsinki, Jyväskylä, Oulu, and Turku. In the club they meet friends, exercise, play games, bake, and do handicrafts. The clubs are run by volunteer social and health care students.

Adaptation training course

Supported by the Finnish Slot Machine Association, an adaptation training course, or Family camp, was organised in the Piispala camp centre in July. The families got to know each other through the programme, games, swimming, and discussions, and shared the strength of being peers.

Sporty rehabilitation course

A sporty course for children of comprehensive school age was organised already for the 31th time with the help of the Social Insurance Institution of Finland. The aim of the course is to exercise the sports skills of school-age children with visual impairments, and to find a suitable sporty hobby that fits in with the family's everyday life. This is why in the course they get to try out different sports, e.g. swimming, paddling, gym training, athletics, and judo. There are also lectures for parents. Naturally, there are also sauna and camp fire nights.

New members gather together

The day of new member families of the Association for Parents of Children with Visual Impairments was spent at Aulanko, Hämeenlinna at the end of October. There were eight families, three energetic children's instructors and our cooperation partner the Foundation for Visually Impaired Children.

The Aulanko spa is a joyful place, and of course the most important part of the day for many children. The parents perhaps appreciated it that they got to sit down at a set table for Saturday lunch.

During 2011, 40 new families joined the Association for Parents of Children with Visual Impairments.

LEENA HONKANEN

■ The three-month-old baby Ella in the arms of her father Juha Sáren was the youngest participant of the day for new families.

JANNE SUOMALAINEN

JORMA VÄISÄNEN

JORMA VÄISÄNEN

Weekend for fathers

The large dining room of Koivupuisto, spacious fireplace room, and transparent Näsijärvi lake provided the setting for the fathers' pleasant stories and larger than life thoughts. There were a few younger heads of the family, and perhaps therefore we had an opportunity to contemplate, even a bit sentimentally, the role of a father in the life of our children.

I can only say that we may after all be cut from a different cloth than the so called average daddies (or were we actually made of iron...?). Common to all of us is that we are very much present.

Some sort of forefather characteristics also started to appear, especially when the cooling night, glow of the flames in the barbecue, and fresh meat products awoke some more primitive feelings. We did not get carried away, but the simple primitive pleasures had their impact on the atmosphere.

Barbecuing and talking continued until the wee small hours. After very little sleep the transparency of the lake Näsijärvi attracted some lonely rowers, and a brisk morning sauna was, of course a traditional part of the programme.

Arto Hippula

JAANA VÄISÄNEN

JAANA VÄISÄNEN

Weekend for mothers

A merry buzz of conversation is heard and greetings resound when the mothers meet in Villa Hiidenmäki. "How lovely to be able to relax!", "A wonderful place!", "We have waited for this!", "Nice to meet you!".

After getting to know each other and a welcome coffee it is time for an outing. There is geocaching in the programme, and we get a quick introduction to it. So, a gps tracker around the neck, instructions in the pocket, and let's go! The awesome Hiidenmäki scenery makes the mothers sigh; the crispness and atmosphere of the autumn forest are good for the soul. And we do find all the five caches – in a shorter time than predicted, even. We are some moms!

After the outing and some small talk it is time for dinner. It is lovely to sit down at a set table, overflowing with delicious food, and no need to do the dishes.

Soon we start thinking about the sauna and hot tub, and in no time we are already up to our necks in the warm water. Such bliss! We are pleased to realise that we are alone and can speak freely amongst ourselves. We are the best peer support for each other and take advantage of the situation. We keep talking as the night gets darker.

Thank you lovely peer mothers, there's plenty of energy to carry on now! And thank you to the Association for Parents of Children with Visual Impairments!

Jaana Väisänen

Special Parenthood of a Special Child

What kind of parents do our special ones make us? Would I be different if I were a mother to a normal child? The disability of a child does not make any parent a better or a worse person. At the worst, a parent can be really off-putting company when always grumbling about the same problems and no halo will light up on top of your head just because your child has a diagnosis. And it does not turn parents into happy survivors who never complain about small things, because matters could be worse. It is everyone's right and a sign that right now things are going well because there is time to address minor flaws.

I have noticed, however, that a child being so different that it shakes the foundation of life encourages one to be just as one is. It can happen in parents, siblings, friends, or grandparents. In the circle of acquaintances surface skills and characteristics that would have gone unnoticed in a regular, uneventful life; immense creativity, gentleness, and tolerance. With a special child the accustomed ways are not valid, but one needs to learn to see and hear what the child wants to teach about themself, and be present and near. Reima does not love anyone out of duty or at the price of plastic toys, but shares his sunny smiles exactly with those people he wants to.

Many parents say that the best thing about living with your own child is to see how quickly the child develops. I think that they do not remember the most essential thing. The best thing is really that the child exists. All parents just haven't had the opportunity to realise how much unselfish love and admiration, uncorrelated to the child's achievements, they have in storage. Naturally, the feeling of attachment does require some response, a thank you expressed with the smallest hints, looks or satisfied sounds, but we parents are the most qualified to read them from the position of the eyebrows or the colour of the tip of the nose. And sometimes from the most self-evident signs. When visiting at the mother-in-law's place, Reima got to sleep between us parents. The boy chuckling with laughter didn't know which way to be, but looked at both side in turns and felt with his hand to make sure that he really was going to sleep between his own parents.

There is one clear difference in being a mother of a non-disabled 3-year-old and Reima. I get to keep Reima in my arms as much as I want. The relationship with the child must be tight physically, and he's always ready to be held. I will probably get to kiss him publicly for a very long time and call him a baby without anyone having to be mortally ashamed.

annariikka.sivonen@gmail.com

■ The Reimakka series tells about the challenges and moments of joy related to parenting a disabled child. Annariikka Sivonen from Joensuu is a public health nursing student and a family caregiver, whose family consists of her child Reima, born in 2007, visually impaired and multiply disabled, and her common-law husband Juha.

A Day at a Time

The story of our family started on 4 September 2004 when our dearly awaited for first babies, the twins, decided to be born without advance notice, much too early (pregnancy week 23+6). In an emergency baptism our sons were named Aleksi and Juuso. In the neonatal intensive care unit, where our tiny boys were taken, the doctor told us right away to prepare for the worst. Our son Juuso only had the strength to live for eight days, but Aleksi proved to be a real "champion". Against the medical odds, he recovered from a stomach operation he was not expected to survive. After many adversities conquered, the problem for our little man became his eyes, that is, retinopathy typical for premature babies took away his sight almost completely. The left eye can

perhaps discern some light and shadows, the right eye is fully blind.

Our Aleksi spent altogether seven months in the neonatal intensive care unit. The first short "furlough", a few hours at home, was allowed at the end of February 2005. While we were rejoicing Aleksi's tiny steps forward, our life was shadowed by Aleksi's dad falling seriously ill. At the turn of the year we found out that he already had widely spread cancer of the stomach area. Aleksi's dad died just less than three months from the long awaited for home-coming of Aleksi.

So life is unpredictable, we can never know what tomorrow brings...

But apparently, we can get over anything, one way or another. We had our dear, close relatives and wonderful friends who had the strength to live through the first year full of sorrow with us after the passing of my husband. I hardly remember anything of that time myself. Still the support and concern of these people continues – a warm thank you to them all for that!

And life carries you...

Today Aleksi is an active 5-year-old boy. Aleksi loves different vehicles and travelling in them, playing the guitar and the piano, swimming, and little boys' stuff in general. This autumn he started already his fourth day care year in the day-care centre near us, where he has had the same wonderful personal assistant all the time. The day care decision made me very nervous as a mother, because Aleksi was still less than two years old when I decided to return to work as a teacher in autumn 2006. After all, I myself was first so afraid of taking care of my tiny premature boy, how could I possibly then let someone else touch him! Our rehabilitation instructor had told me that regarding day care issues, we would get help from the ambulatory special kindergarten teacher who would come to our home to consider with me, what is the best option for Aleksi. After discussing with her in March the same year, I was convinced that the day care close to us was what she had described, that is, the atmosphere was open and the personnel were used to different kinds of children. However, they had never before had a visually impaired child. I went to see the place myself right away, and together with Aleksi several times during the summer. And now I feel lucky to be able to state that the whole day care centre – not only the groups where Aleksi has been – does a valuable job from the heart. All along I have been delighted by the way how the workers of the other groups – from the very start – have told Aleksi their names, and greeted and touched him when they passed. Aleksi has been in two different groups both of which have had nurses beyond compare. It has been a joy to see how ready they have been to help and understand Aleksi, so that he can be part of the group just like any other child. Naturally, a very special person for Aleksi has been his own nurse Niina, whose enthusiasm in gathering information about visually impaired children and applying that information in practice has been incredible. And as we all know, it is not easy for a visually impaired child to become socialised with other children, eat and so on, not even at home, and less so elsewhere. The greatest joy for me as Aleksi's mother has been, of course, that every single morning Aleksi has been happy to stay in day care, and has happily waved goodbye to his mother. During this year Aleksi has started to speak more in the day care as well, and he has become more social, and independently seeks contact with the other kids and plays with them. At the moment Aleksi gets three types of therapy, which are mostly implemented in the day care. We have also been lucky with the therapists and all the people working with Aleksi, because they seem to be genuinely interested in my visually impaired child's issues.

Life with a small, almost blind child is naturally often hard and demanding, especially for a sole caretaker

And a lot has gone into these past five years. It has been a great pleasure to see how well things are in Finland for visually impaired children, after all. Aleksi has his therapies, we are able to participate in courses and camps organised by different parties, and there are get-togethers organised for visually impaired children even in our own town, so peer support is readily available. During these years I have also learned that Aleksi will learn things, I must just remember to be patient and give him time, and not waste time pondering over what other kids his age can already do. We progress at our own pace, taking small yet important steps forward.

Aleksi is a miracle with a capital M as such

When I look at this laughing and witty darling, tears often well in my eyes, how proud I am of my own child! Life will likely scatter many things in our way, but to me life is too valuable to be wasted on worrying about things in advance. It is enough to fully enjoy this moment and try to live as well as possible today. A day at a time: that is enough.

Text **Leena Honkanen** *Published in Silmäterä 3/2009*

Hattifatteners are Particularly Special

The Hattifatteners of Tahvonlahti day care are a special integrated group of twelve children, where the five children in need of special support also get it from their group mates. The four adults of the group take care that life in the day care is nice and smooth.

Jimi is a four-year-old boy with low vision, and a Hattifatteners. He joined Tahvonlahti a year ago in the autumn and has adapted well to the ways of the group. Jimi coming to the day care required some advance planning, of course, although in this case we were so lucky that the special kindergarten teacher **Heidi Honka** already had had experience with visual impairment.

"The rehabilitation instructor of the Central Hospital visited the day care, and we thought of the changes and aids which would be needed for Jimi to cope as independently as possible. We have managed with very few changes. We improved the lighting a bit and Jimi was given his own sign on the back of his chair, in the clothes rack, and next to his own towel. Now the sign on the chair has already fallen, but Jimi can find his own place."

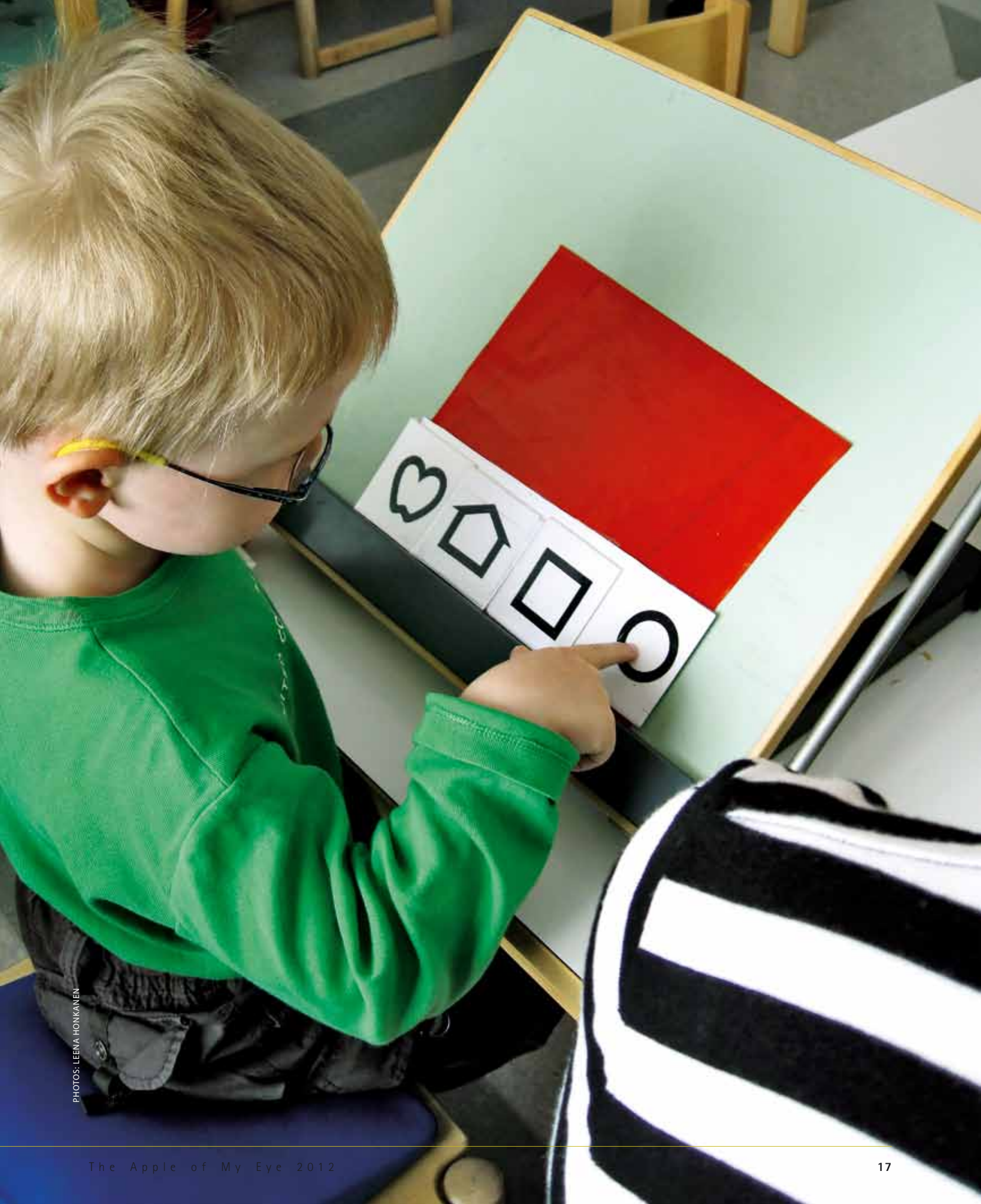
"Beforehand we wondered perhaps most about how the everyday life will begin to sort out and how Jimi will learn to navigate in the day care premises, which are a bit rambling. We had planned to mark routes on the floor so that Jimi could find his way from one place to another, but he learned the routes already before we had had time to glue the lines."

Together and in peace

Heidi Honka regards peaceful and safe day care routines as the basis for everything. It is important that everyone feels that they belong to the group.

"When they can be of help and act as a model for special children, the self-respect of the other children in the group increases. It is also good that an adult is truly involved in the daily routines. For example, we, the adults in the group, eat at the same low tables with the children, one adult at a table of three children. This way the eating situation remains peaceful even if there is a child at the table who's a bit of a handful."

■ A raised desk was practically the only special aid purchased for the day care centre for Jimi, otherwise we have managed with the things brought from home and by being resourceful.



PHOTOS: LEENA HONKANEN

Dressing goes well when there is no need to rush, and there is a safe adult nearby to give advice should there be a problem.

"Jimi, like many special children, needs a bit more time and repetition at the table, but we are not in a hurry. Eating has started to go really well, and Jimi now has the courage to try many kinds of flavours."

"A visually impaired child should always be placed in as small a group as possible. A personal assistant is also important, but the assistant must be able to give the child room for coping independently, and gradually move aside as the child starts to cope with situations on their own. Every child can be asked to do what they can, and children can, given the chance."

Education is a team effort

"An honest and trusting relationship between day care and home is the cornerstone of an educational partnership. The affairs of special children are not discussed in the corridors of the day care centre. They remain confidential between the parents and group instructors," says Heidi Honka.

"Children selected to support the special children in an integrated special group are there because their parents wanted their child to be in this group. Sometimes the parents may wonder if their child gets enough attention when there are several children in the group who need special support. On the other hand, the benefits of a small group and the number of day care nurses tempt others to join the group. To me it seems that here Jimi has truly blossomed and has found his place among the others."

In Tahvonlahti there are altogether about a hundred children, and in addition to the children of the Hattifattener group, many of the others also need special support. The day care is also highly international, about thirty per cent of the children come from immigrant families. Heidi Honka regards this as a good thing.

"Here all the children are used to the fact that there are different people in the world. This is a world common to all of us. All children must be allowed to be as normal as possible. The task of special education is actually only to detect the individual needs of a child and help the child overcome the obstacles."

Play tips

for a day care group with a visually impaired child

Sheet dance

For a sheet dance you need a sheet and music. The players grab the edges of the sheet and move up and down and around as a group, in time with the music. Some of the children can be under the sheet if they like.

A memory game with sound jars

The instructor prepares sound jars. Empty film containers make good sound jars. You place, for example, rice, macaroni, stones, breadcrumbs, and bells inside them. There have to always be two similar sound jars. The players listen to the jars and try to find the matching pair for their jar.

Bloodhound

The children stand in a circle. One of the children is chosen as a bloodhound in the middle of the circle. The child gets to sniff different distinct scents. Such scents can be, for example, dill, black currant, and salmiac. Then one of the scents is hidden in the hands of a child. After that all the children make a fist and the bloodhound gets the sniff the hands and find out who has the scent. The hound will bark at the child who the hound suspects to have the scent. When the scent is found, a new bloodhound is selected.

Anne Latva-Nikkola

Text **Leena Honkanen**
Published in Silmäterä 3/2010

The Girl from a Sheep Farm

Eerika Toivola lives in the middle of most beautiful countryside in the municipality of Iitti, village of Mankala. The hunger for learning and lively imagination of the girl, who is blind from birth and suffers from rheumatism, bypass the limitations of the disability and illness; the thirst for life carries the eight-year-old to new adventures.

A hot July day is at its most radiant when we drive to the parish camp centre to meet **Eerika** together with her parents **Tuula-Anneli** and **Perttu Toivola**. We are accompanied by her ten-year-old big sister **Henriikka**.

Eerika feels right at home with the other forty plus campers. She shares a room with four schoolmates. Tossed on Eerika's bed are her wrist supports, which she has to wear at night because of rheumatism.

"Blindness is the smaller problem for us compared to the severe rheumatism," says Tuula Toivola. "Eerika's medication for rheumatism is as strong as it can be, and the treatment periods and operations are tough. The closing of the Rheumatism Foundation Hospital in Heinola has hit us and the other patients hard."

"However, I am happy that Eerika adjusted so well to the situation. We try different hobbies depending on how the rheumatism allows them. A year ago Eerika started playing the accordion and it is going well."

In the neighbouring municipality live a blind accordion virtuoso **Joose Ojala** and his brother **Tuukka**. Even though the Ojala boys are much older than Eerika, Tuula-Anneli Toivola is happy about these friends, because there really aren't other blind children in Eerika's age group. "Even during the periods at the Jyväskylä School for the Visually Impaired there are only two boys there with Eerika."

Animals and the rest of my family

The four hundred sheep farm of the Toivola family is one of the biggest sheep farms in Finland. Eerika mentions that she has fed the sheep with dandelion leaves and has held a lamb on her lap, but she is not overly enthusiastic about sheep. There is a reason: the snout of big ewes butts Eerika at head level and that does not feel nice.

Instead, a Pyrenean Mountain Dog named Chiro with its soft fur is Eerika's pet. Chiro lives indoors; the family's other seven dogs stay in a dog kennel. They are sheep herding border collies. A few cats are also members of the Toivola animal world.

In addition to her father and mother, her big sister Henriikka is part of the family. Henriikka says that she's not that interested in playing with the little sister anymore, but when the girls have sat next to each other on the bed for a while, a sisterly squabble starts. In a village of about ten people there really aren't other playmates to be found.

"Eerika can still play with cone cows, but Henriikka is already more interested in teenage stuff," says their mother. "However, even if they keep some distance at home, they do stand up for each other should a schoolmate bother one of them."

Eerika spends a lot of time with books. She can read braille so well that braille books beat audio books. When Henriikka has to switch off the reading lamp, Eerika may continue reading in the dark.

Third grade in the autumn

Despite the full summer bloom at the time of this interview, we talk a little about school, as well. The linguistically talented Eerika finds going to school, reading and learning new things nice.

The distance to the nearest school is over ten kilometres, and both girls use school transport to get there. The Kymentaka School is a small primary school with 33 pupils, where two consecutive grades always study in the same classroom with the same teacher. Eerika has her own school assistant, Minna, and they get along well both at school and during their free time.

When Eerika starts third grade and Henriikka fourth grade, the Toivola girls will be in the same classroom. According to the girls, it won't make things more difficult or easier.

Tuula Toivola says that they've had to negotiate with the municipality about Eerika's needs, but in the end, everything has been going well. Now the school even has a braille printer. Prior to that, the teacher typed all the material Eerika needed with a braille typewriter.

For a girl from a small village, school is also a place where she meets other children. At school Eerika has friends and she plays together with the sighted children. A good recess game is stick tag, where Eerika can use a thin stick as an aid when she's the tag. "I cannot remember who thought of it, but we've played it since the first grade," tells Eerika.

Parent's resources

When we are about to leave the camp, the camp manager Tanja asks Henriikka if she would like to stay at the camp – there are still a few camp beds free. Henriikka loves the idea and thus the parents suddenly have a few days for themselves, if not time off from farm work. On the way back the adults' talk turns to coping.

The last holiday the Toivolas had together was their one-week honeymoon trip in 1993. Farming does not allow such flexibility in which the whole family could travel together. Eerika's rheumatism requires warmth, and therefore the mother takes the girls to the south for a week in the autumn and the father stays behind to take care of the farm.

"Honestly, I have to admit that it has been difficult at times," says Tuula Toivola. "I am not at all surprised that there are so many divorces in families with disabled children. We have had our share of argu-

■ Eerika, Chiro, Henriikka and Ella, a friend of the girls visiting from Helsinki for the summer.

ments, too, when there have been longer periods in which the ability to cope has been at a zero level."

Tuula Toivola is distressed by the fact that they lack a safety network of relatives. "The girls' grandfather, the previous farm owner, is already 83 years old, and the grandma is in heaven. My parents live in Raisio, so we cannot get help from them at short notice, either. Luckily, I have made new friends in Iitti, who have become 'backup grandparents'."

Taking care of the children and the farm, Eerika's rheumatism treatment periods, operations, therapy, and the mother's three-shift work as a nurse at the health centre set the boundaries for the schedule. "One just needs to learn to adjust the line to what is necessary," says Tuula Toivola.

"A sheep farm follows a very different rhythm compared to, say, a milk farm that has a regular daily schedule. Sometimes there are only a couple of hours of work in a day, but when many ewes give birth at the same time, there can be work for twenty hours," describes Perttu Toivola.

"We don't know about the future yet," says Tuula Toivola. "Perhaps we will give up the sheep some day. We want to secure the girls' future in some way. Whatever they will do when they grow up, the fields and forests of the homestead will be their nest egg."

■ The Toivola family describe themselves as a family that is different in many ways: Eerika's blindness and rheumatism and the big sheep farm make the family's life unusual – sometimes tough, and sometimes lovely.

Possibility Play

Physiotherapy is usually the first of all forms of therapy. Physiotherapist **Katariina Nyyssölä** often starts therapy already when a baby is two–three months old.

"In case of a small baby, I am still not able to say what the direction of the development will be. At first therapy is about observing and analysing. First, a relationship based on trust must be created with the baby. One must adapt to the baby's rhythm and wait for the baby's reactions. This is how the interaction starts to gradually work."

"Therapy can be very slow; some may think that a therapist's work is only about playing and entertaining the child. Every child has the right to play and the right to be a child. This is why we have to dig out ways of how a child gets an opportunity for playing in his or her own way. A therapist must see the small steps and also highlight them for the parents. Every new achievement is worth celebrating," says Nyyssölä.

Familiar through the sense of touch

The starting point for the physiotherapy of a small, multiply disabled baby is sensory stimuli. A therapist observes how the infant starts to use their sight and discern their body.

"A two–three-month-old sighted baby already starts to follow a toy with their eyes and reach for it with their hand. With a multiply disabled child you can

Text **Leena Honkanen** *Published in Silmäterä 4/2008*

for and Interaction

The physiotherapy of a multiply disabled child progresses in small steps. A therapist helps the child to find a connection to their own body and to the world around them.

try, for example, following a bright light if toy does not seem to be interesting," tells Nyyssölä.

Sense of touch is used to create an interactive relationship with a baby

"A baby gets a lot of information and experiences through the sense of touch. That is why it is important that a baby is handled confidently, so that the baby feels safe. A baby also learns to discern their body with the help of the sense of touch. For example, awareness of limbs comes through the sense of touch if the child cannot see," tells Nyyssölä.

"In physiotherapy the sense of touch is stimulated in many ways. In addition to normal massage, different materials are used to provide stimuli for the sense of touch. Soft brushes, different cloths and vibrators are good tools which provide different sensations of touch."

Sound encourages communication

According to Katariina Nyyssölä, the strongest sensory stimulation is provided by sound. A child becomes interested in a toy which enables them to produce a sound by touching or pressing it themselves. At the same time we are already a step closer to communication.

"Using buttons is an easy way to communicate. They make it possible for the child to express their needs, even if there is no speech. Little by little the child notices that they can, for example, ask for something, like more music, for instance, by pressing a button. At that point they have already started to have an impact on their own things."

"If a child can see, pictures can be included to help communication, but that is already a considerably more demanding way. Picture communication usually starts with the basic words 'no' and 'yes', described by a cross and a smiley face, for example. Communication with pictures also requires some amount of the use of hands, because the child must be able to point to the picture they want."

"If the use of buttons and pictures does not succeed, to be able to read from the expressions and gestures of the child what they want or don't want can be regarded as sufficient communication. A blink of an eye can be enough "This, however, requires a very tight and close relationship with the child," tells Nyyssölä.

"Communication practises naturally take place already as a baby, but often the actual speech therapy starts only at the age of two, and the goal is that the child learns by themself to influence and express their wishes.

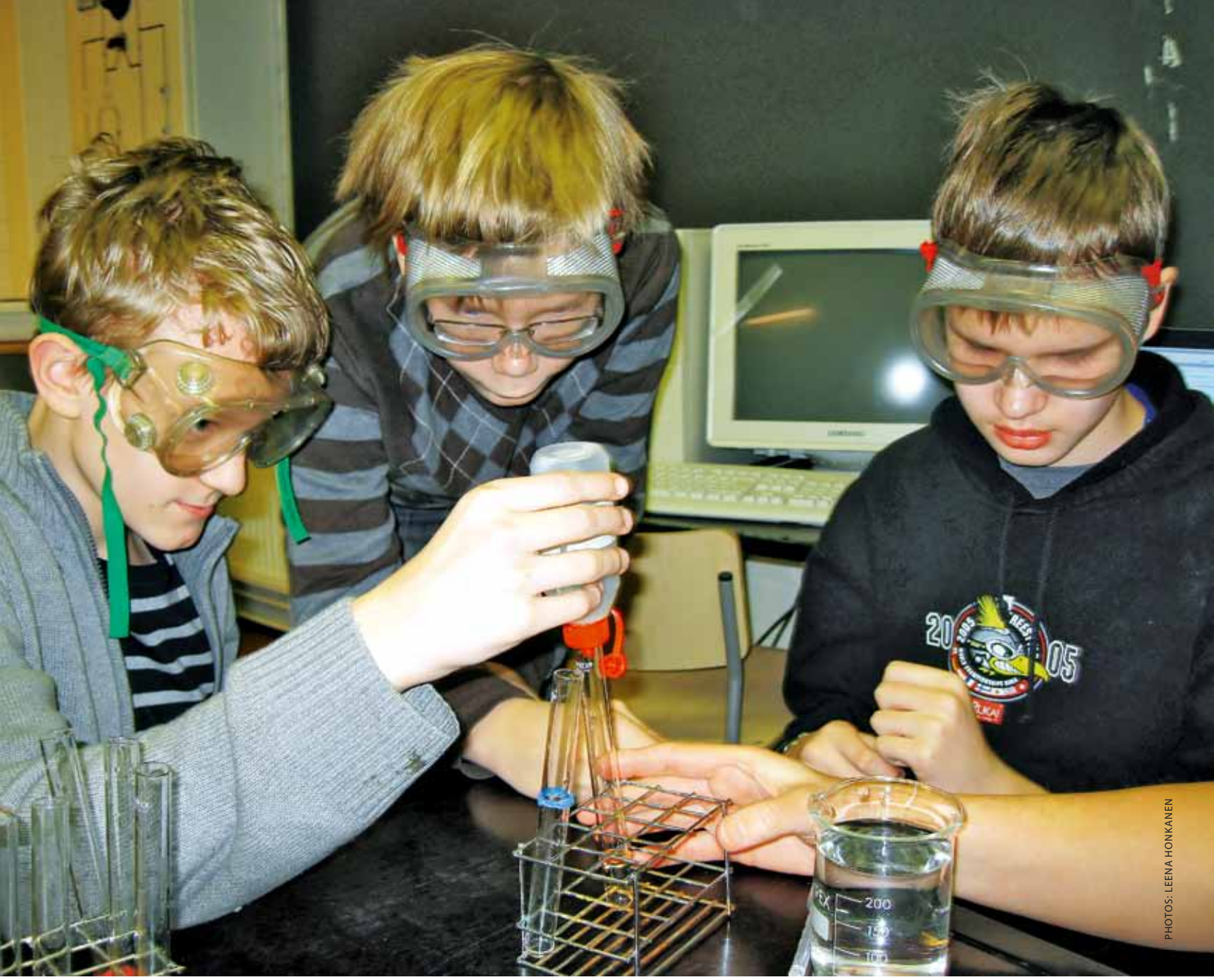
Need for therapy is assessed regularly

"Everyday life is an important part of rehabilitation. Supporting the development of a multiply disabled child requires a lot of strength from the family," says Katariina Nyyssölä.

"The illness and condition of the child define what and how much they can practice, and on the other hand, the parents' own resources must be considered. Rehabilitating activities are usually scattered amongst normal routines. A play situation can be organised, for example, in a standing rack, so the child will practice body control and putting a load on the lower extremities."

"We must always remember that this is the family's child and life and their choice. It is most important that the child gets to be a child, not a disabled child. For a child it is most important that people do things and play with them," emphasises Nyyssölä.

Once the physiotherapy progresses, it starts to be visible into which direction we should continue, what other possible therapies could be of use, and what kind of communication methods should be taken into use. At first the need for therapy is assessed closely, even every couple of months. Public health care will create an estimate and the therapy is first paid for by the Hospital for Children and Adolescents, later by the Social Insurance Institution of Finland. The therapies of multiply disabled children are often very long, lasting for years.



PHOTOS: LEENA HONKANEN

Lassi's School

Lassi Alahäivälä (13) started secondary school at Variska school in Vaasa last autumn. The school has welcomed its first blind pupil well.

Text **Leena Honkanen** *Published in Silmäterä 1/2009*

A lesson in chemistry is underway, and the topic is reaction speed. Jussi and Matias get the test tubes, water, hydrochloric acid, and other required equipment and come to Lassi's desk to perform the test. The teacher, Anna-Liisa Haapaniemi has stored the written instructions on a memory stick for Lassi.

The assistant, Raija Karjalainen, follows the progress of the test and together with Lassi listens to the hissing of the test tube and hands out magnesium grain and powder to feel. Then Lassi records the test results on the computer.

Anna-Liisa Haapaniemi has been happy about her special pupil, who has provided new challenges for teaching work.

"Teaching chemistry to a blind student is not difficult. I got good tips in a course at the Jyväskylä School for the Visually Impaired. It has also been educational to hear a blind secondary school pupil tell about his school experiences. In the lesson, Lassi does all the same tasks as the others; some things just need to be adapted a bit. "Lassi's own assistant Raija Karjalainen has already been involved since primary school, so her competence and experience has really been helpful," emphasises Haapaniemi.

Well prepared path

Headmaster Päivi Kaarniemi had to solve the issues related to the curriculum and teaching premises when it was known that Lassi would start school at Variska.

"In the secondary school the subject teachers have their own subject specific classrooms. For Lassi, moving from one classroom to another with his equipment between the lessons would be inconvenient, so we were presented with a request that for his class, a home classroom of their own would be organised. We managed to turn the Finnish classroom into one."

"We started to prepare for Lassi's arrival in good time already during the previous spring, so everything was ready when school started in the autumn. We have been able to send about a dozen teachers to a course at the Jyväskylä School for the Visually Impaired, with the help of the stipend fund administered by the Vaasa School Authority."

"None of the teachers expressed any negativity about Lassi joining their teaching groups. The only question many had in their minds beforehand was how to be able to teach a blind pupil. The uncertainty quickly evaporated once school started in the autumn. Lassi's assistant is a top professional, a real treasure, who has brought in knowledge and skills we can always rely on. Lassi's father, is a teacher at our school, so he has also been there for support when there have been questions.

Teaching challenges

Lassi's teachers seem to regard the current autumn term as a success. They commend Lassi as a diligent and smart pupil, who has introduced new viewpoints to teaching.

Anu Kallio, Swedish Teacher, regards it as a challenge that during a lesson, it is customary to do many different things, jumping from an exercise book to a text book and back.

"Now this jumping has been cut down a lot. The day at the Jyväskylä School for the Visually Impaired was also very rewarding. It revealed how information technology can be used in the teaching of a blind student. An electronic workbook functions really well, and I can make exams for Lassi on a memory stick. During the lesson we also have to take into consideration that all instructions must be provided orally."

Tuija Nabb, Religion and Social Studies Teacher has thought of methods for telling about the topic to be taught in a lively manner.

"During the lesson we read aloud and discuss a lot. I aim to provide clear examples and describe things as well as I can. Currently, we are covering the major world religions. I am trying to find objects and outfits related to the topic, which provide more information to the sighted pupils, as well. Small Buddha statues have been studied and the minaret call has been listened to. In the spring when we move on to Judaism, I was thinking that Lassi could listen to Anne Frank's diary as an audio book."

Lassi and his assistant Raija Karjalainen in a home economics lesson.

Home economics teaches independence

A busy school day is drawing to its end. Lassi has home economics and the pupils are preparing Christmas dishes. It smells wonderful and the group of ten boys are bustling away happily. Hannele Hakkarainen, Home Economics Teacher, has already thought of new arrangements in the home economics classroom, if Lassi decides to continue taking home economics in eighth grade.

"In the future, Lassi will get his own permanent work point in the lesson, and we can mark the spice jars and cupboards with braille. Home economics is an important subject for the development of skills needed for an independent life; food is a part of every day, be it a normal day or a celebration.

At the Jyväskylä School for the Visually Impaired I received information about the facilities which help Lassi work during the lesson. During the autumn term I have noticed how many things must be considered in advance in the teaching of a blind pupil. The help of the assistant, **Raija Karjalainen**, has been an absolute must, because everything new has to be taught hands-on.

The work day of the pupils ends, and Raija walks Lassi to the taxi. She will still need to do preparations for the next day. An assistant has 37 weekly working hours, out of which 30 are reserved for helping Lassi in the classroom, and the remaining 7 for the preparation work.

"A Cuckoo Song Sounds… Red"

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The income received by selling the DVD is spent on recreational activities for families with blind children.

Text **Ronja Oja** *Published in Silmäterä 4/2011*

Change in Life with Gas

I moved again. In my life I have moved altogether six times, three of the moves took place during the last three and a half years. This time I moved to live with my boyfriend in east Helsinki.

Moving is boring and exhausting. On the other hand, it can also be fun, anticipated, and great, but the moving process itself is always boring and tiring. Luckily, I likely won't have to do it again for a very long time.

When you are blind, it is important that you get to put your things in their places yourself. It really does not work out if someone else organises the things in the new home. When the places are still unfamiliar, at least the things should be in a familiar order - or at least decided by myself.

We moved while I had to study for the matriculation examination. So I couldn't be there all the time organising things because I had to read. And so the dishes found their place without my presence, as did the biggest part of my bookshelf. For a while I was irritated over what I thought was the wrong order and not being able to find anything, until Mikael – that is, my "common-law husband" – came and went through the cupboards with me. "Now, it would be so silly if you didn't know what is where in the kitchen."

Quite often different flats have a bit different stove, for example, and one has to learn for a while before being able to use it properly. However, the change is not usually quite as dramatic as it was for me in this move: we have a gas stove. I have not previously dealt much with gas stoves, although my family's camper always had one and I used to watch it thinking "what a nice blue flame". Now I had to learn to use gas for cooking, because I didn't want to live on microwave food alone.

At first my circle of acquaintances regarded the thought of me with a gas stove mostly as a safety risk. I wondered myself if I would succeed in blowing up the whole flat within the first month. I did not. I don't know how safe my circle of acquaintances still thinks a gas stove is for a blind person, but I don't think that it is a problem anymore; a gas stove even makes a sound when it is on. And I cannot leave the gas on accidentally if there is no flame in the stove, because it shuts off automatically when you stop pressing the button.

Our gas stove needs to be lit with an external source of fire, a lighter or matches. We have a lighter with a fairly long handle and it only gives a sparkle. It is easy to light the gas stove with it: first I find the right place for the tip of the lighter and only then turn on the gas tap. I have not managed to cause any damage yet (well, I did actually scorch the tips of my hair once), but I sometimes manage to accidentally switch off the burner when I turn it lower.

When I first moved away from home I was afraid of going to a shop, the amount of house work, and moving around independently. The second time the biggest cause of excitement was the scarily busy Mäkelänkatu street which I had to cross on a daily basis, again a new grocery shop, and all the new routes. Now, after the third time, shopping and house work have become more of a routine (it can be that someone does not believe the latter point), and there are quite a few routes I already know, and I haven't had to be afraid of anything else than the gas stove and how I will be able to put up with my boyfriend nonstop. The fears have again proved to be unfounded, and I can happily state that one can survive anything, and in the end, moving is a positive thing.

PHOTOS: LEENA HONKANEN

The home country, crippled by war, could not offer care or rehabilitation to a visually impaired small child. Medina's family got the opportunity to come to Finland in 1996, through the international humanitarian organisation IOM. Medina was three years old at the time.

The cause of Medina's visual impairment is septo-optic dysplasia, a congenital anomaly of the central nervous system where optic nerves are under developed. Medina can only see light. Her mother **Sanela Omeragic** says that she would have unnecessarily made her daughter helpless and lacking in independence if she hadn't gotten the information offered by the Finnish rehabilitation system about bringing up a visually impaired child.

"During the first years I did everything for Medina, because I didn't understand that a blind child can learn and cope just like anyone else."

"In Finland Medina got to go to day care and had an assistant there. Learning Finnish was not difficult for her. At first the two languages got mixed and there were some blunders with the language, but in the end Medina learned Finnish quickly and other development took off as well."

Tenth grade and profession

Medina goes to the Toivola special school with a hundred students. Her favourite subjects are English and handicraft.

"The school is rather big, rambling and noisy, but I have learned to cope well there. I also have some friends at the school," tells Medina.

In the evenings after school there is time for hobbies and the computer. All Medina's hobbies are related to art and culture: reading, writing, and music. Al-

Text **Leena Honkanen** *Published in Silmäterä 1/2010*

Medina's Good Life

Medina Omeragic was born in February 1993 in the middle of the Bosnian war. Now Medina lives the safe life of a Finnish schoolchild and dreams of going to the 10th grade of the Jyväskylä School for the Visually Impaired.

though she listens to audio books in Finnish and writes stories in Finnish, she also needs to keep up her Bosnian language skills.

"When I was small my mother read fairy-tales to me in Bosnian. Nowadays, I download stories in Bosnian from the Internet and chat with my relatives in Bosnia.

Now that the comprehensive school is almost over, the young lady is thinking about the future.

"After comprehensive school I would like to go to the 10th grade of the Jyväskylä School for the Visually Impaired. My visually impaired friends, who I have met and become friends with during the support periods at the Jyväskylä school, will be there. Then after 10th grade it will be time for vocational studies. I'm now interested in massage and artisan work, but these professional dreams change quite often," confesses Medina.

Two of us in a foreign country

A few years after coming to Finland Medina's father return to Bosnia and mother and daughter were left here to build their life together. Sanela Omeragic is happy that she has been able to offer her daughter an opportunity to grow up in a country where visually impaired children are well taken care of.

"The situation for visually impaired children in Bosnia is still not good. There is a school in Sarajevo for the visually impaired where a child can be sent. They cannot go to a regular school unless the families get all the necessary aids themselves. Since the standard of living in Bosnia is still low, many families cannot afford to buy even a white cane for their child. I have bought and sent canes to some of my acquaintances there."

The relationship of the teenage daughter and her mother is a loving one, but Medina also yearns for a more adult life of her own. She has gradually started to learn the skills needed for an independent life. "Sometimes I vacuum my room and prepare a snack for my mother. My mother enjoys it because there has never been anyone around to help her."

"I think my mother intends to decide about my bedtime until I am 50 years old! Yes, I like it at home and could live at home with my mother, unless I happen to get married."

The republic of Bosnia-Herzegovina is located on the Balkan Peninsula, and it is a member state of the European Union. It has a population of 4.6 million, and the capital is Sarajevo.

The Bosnian war occurred in 1992–1995. It took the lives of about 200,000 people and hundreds of thousands were injured. Over two million people had to leave their homes.

■ Medina dreams of 10th grade in Jyväskylä. She believes that she would not miss her mother a lot during the school weeks in Jyväskylä. And one can always call, if one feels like it. The one-year-old poodle Bingo will also wait for her at home at weekends.

Text **Leena Honkanen** *Published in Silmäterä 3/2011*

Therapy on Horseback

The beautiful mare Jennifer stands calmly waiting for the riding lesson to start. Six-year-old **Santtu Aaltonen** grooms its back with routine. "Feel if there is still sawdust on Jennifer's back," suggests **Minna Laitila**, Riding Therapist.

Santtu places a blanket on Jennifer's back and fastens the saddle girth.

"In horseback riding therapy we do not usually use a saddle so that the rider can feel the warmth of the animal and movements easier," explains Minna.

Santtu starts to walk the horse to the ramp. "The latch is on the right side of the gate," instructs Minna, and the latch is found. "Shall we go ride in the forest or on the field?" This time the field is selected.

"About every other time we go into the forest, and every other time we ride on the field." In the forest the contour of the terrain adds to the experience and challenge. There we also listen to the sounds of the nature and smell the scents. For some who undergo therapy a horse can be the only chance to move around in the nature. On the field we trot, follow the tracks, and learn about directions. I draw a picture on Santtu's arm about the turns of the track so that he can have a mental image of the route in advance. In addition to body control, riding and stable therapy develops many skills from dexterity to using the senses.

Everything had to be relearned

Santtu mounts Jennifer from the ramp and the trio head towards the field, led by Minna. Santtu's mother **Virpi Aaltonen** proudly watches the progress of the rider with great posture.

Four years ago the life of Santtu, then approaching his third birthday, was that of a normal little boy, until everything suddenly changed. Because of a congenital heart defect some corrective operations had already been done on Santtu. A decision was made to carry out a major total repair of the heart in summer 2007. The ten-hour operation was challenging, but succeeded excellently. The recovery began, and four days from the operation they were already moving Santtu to the ward, when he suddenly had an arrhythmia. Resuscitation took over two hours. The result was brain damage.

"Santtu's life was saved, but there was a fear that the ability to move, speak, and see would never return and Santtu would remain a bed patient. During the doctor's examination Santtu did not even react to light," recalls Virpi Aaltonen.

The six months after the operation were a stressful time in the Aaltonen family.

"We spent the first six weeks in Helsinki, and stayed at the McDonald's house, after which Santtu was transferred to Tampere, and we could live at home again in Valkeakoski. I took time off from work

PHOTOS: LEENA HONKANEN

so that I could spend the days at the hospital with Santtu. We had a hard time with emotional strength and family finances. Jussi-Kalle, Santtu's older brother by three years, missed out on the normal everyday life of a child during that time, because our life inevitably focused on Santtu's recovery."

However, Santtu gradually recovered, way above expectations. He learned to support his head, sit, talk, and walk again after he was just over three years old. "The cerebral visual impairment is still classified as severe, the degree of disability is 80%, and the sight varies on a daily basis. Now when school starts he will learn braille. Santtu will become a so called user of two technologies. At school he will have at least a reading television as an aid."

Therapy helps

Santtu's situation was so severe that there were no arguments over the necessity of therapies. "We easily got physiotherapy, occupational therapy and speech therapy. Since I had done horseback riding, I knew that riding therapy would be beneficial, not only for body control but also for the heart. Santtu's heart defect prevents him from doing very strenuous sports, but the heart is a muscle and it is absolutely beneficial for it to exercise as much as possible. A visual impairment restricts many sports. That is why riding seemed like a good option and truly important for balance and muscle control. Therefore, I decided to ask for riding therapy for Santtu, as well; to get it, I did have to make a bit of an effort."

"Santtu received his first 10-time riding therapy period through a referral from TAYS (Tampere University Hospital) from Kela in summer 2009. Back then we visited therapist **Christel Wutig-Vihma** and the excellent therapy horse Masser in Vesilahti. It was a large but kind and peaceful Finnish horse." "In the next neurology session at TAYS they unfortunately thought that Santtu no longer fulfilled the criteria of riding therapy; e.g. there were no more differences in the sides, even though the riding therapist thought that Santtu would still benefit from the therapy." "I was wondering how Santtu could continue riding. Normal riding lessons with someone walking the horse would not be that beneficial because Santtu's recovery would require target-orientation which is part of the therapy. And it would be too expensive for us, anyway."

"While on a holiday organised by the Support for Visually Impaired Children in Ilomantsi, **Rilla Aura-Korpi** encouraged me to apply for support from the Foundation for Visually Impaired Children, which grants support for hobby activities, among others. So I made the application. To our great joy we got an affirmative decision and Santtu got to ride twelve times in summer 2010."

"After I received the decision, I called our riding therapist, who told me that she might not have time to take Santtu to therapy, because she only had one horse and many people to rehabilitate under the Kela contract. She recommended a riding therapist in Valkeakoski, Minna Laitila, whose horse used in the therapy, was kept quite close to our home, and that way we got to go riding already in the spring."

"I also applied for support from the foundation for this spring and we were in luck again: riding will now continue for ten times. Riding days are days waited for and looked forward to, and we enjoy them, both Santtu and I, when we get to go out to the nature once a week. I hope that other children who could benefit from riding and stable therapy would also get this opportunity. In the therapy Santtu has learned to control his body and has gained courage to move despite his visual impairment.

We will meet again in the autumn, Jennifer!

The last therapy session of the spring is about to end. Jennifer is already looking forward to spending a peaceful evening in her stall after the day's work. Santtu takes off the blanket, fingers the saddle belt buckle open, and takes the gear to its place in the corner of the stable. Then he gives a piece of crispbread to Jennifer.

Santtu still has stable work to do, which he likes a lot. He fetches water and goes with Minna to the saddle room to wash and grease the bridle. After that it is time to say goodbye to Minna and Jennifer for the summer. There are still four therapy lessons left for the autumn. Now a lovely summer with holiday plans lies ahead, and after that the exciting but pleasant start of school.

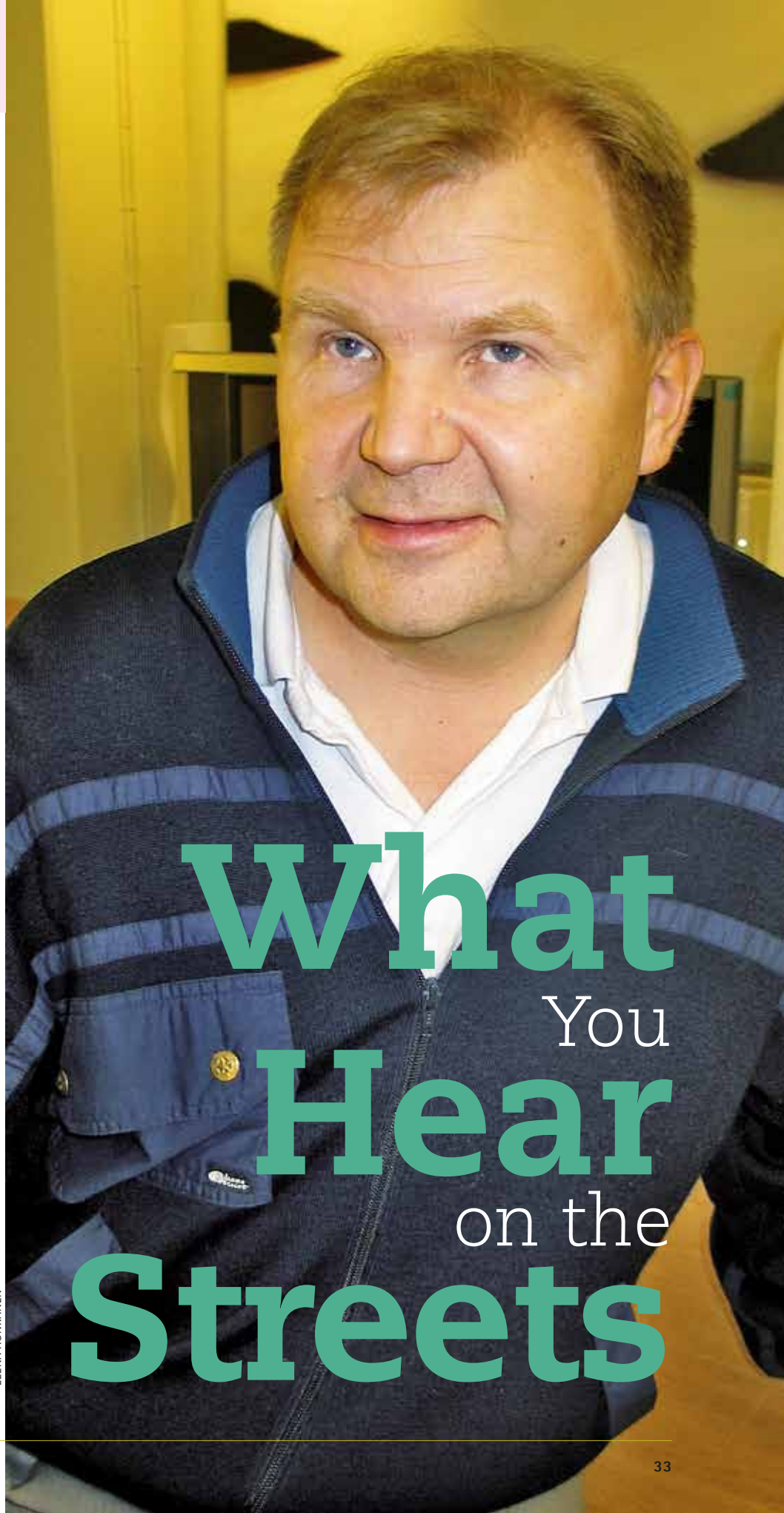
Text **Leena Honkanen**
Published in Silmäterä 1/2008

What You Hear on the Streets

When perceiving the environment every sense is important. The more senses convey the information, the more confidently one moves. In a cross-modal environment one can also manage when blind.

Jukka Jokiniemi (45), Doctor of Technology, has worked for years for a more accessible and better defined environment. Last November one milestone was passed on the way to a more accessible design for the visually impaired: Jokiniemi defended his doctoral thesis on multisensory urban planning. The thesis provides explicit information to encourage designers to avoid design errors and expensive repairs afterward.

The thesis examined accessibility from the aspect of using traffic light voice guides, outdoor lighting, contrasts, and sense of touch. Natural sounds, for example, birdsong in voice guides proved to be functioning. The study also revealed the asymmetry of the seeing of contrasts:



LEENA HONKANEN

■ Jukka Jokiniemi defended his doctoral thesis on urban planning at the University of Technology in 2007.

the contrast of a dark stripe turned out to be clearer than the contrast of a light one on all of the backgrounds examined.

Senses work together

Sensory affordances in the environment, detectable with different senses add to the confidence of a visually impaired person.

"One can get information about the same thing through several different senses, and the more cues there are available, the more confident one feels - naturally, provided that the observations are not contradictory," says Jukka Jokiniemi.

"When the same information comes through several different senses, 1+1 is more than 2. The observations expand upon and strengthen each other. It is important that the information is harmonious so that it is perceived as coming from the same source and conveying the same message."

If more stimuli are added to one and the same sense, it does not produce the same end result; in this case, 1+1 is less than 2.

"Regarding people with poor eyesight, it is important to rehabilitate the remaining sight; no matter how slight it is, because even minor information received by it is still an additional confirmation for the information transmitted by other senses."

"For the blind, the audio landscape and information transmitted by the sense of touch are emphasised: guiding materials and walking surfaces."

Sound is a map for the blind

For a completely blind person, the sound elements of the environment are particularly important. A diverse audio world consists of both technically produced and natural sounds. In addition to aural beacons and voice guides for traffic lights, the route can be found based on the slam of an elevator door, escalator clatter, or a corridor with an echo. All these also provide additional information for the weak-sighted and sighted as well.

Thesis City for All Senses – Accessibility and Cross-Modality in the Built Environment handles urban planning through cross-modality.The work examines urban planning from the viewpoint of accessibility for the visually impaired.

"A silently opening sliding door, or an elevator silently gliding to the floor does not provide a blind person with information about a clear route," says Jokiniemi.

"On the other hand, there can be too much information. Too many traffic light beepers at a crossing may make it difficult to detect the direction of the sound. In audio planning there are numerous aspects to be considered."

"A good guiding sound easily reveals the direction and stands out from the background noise. This is affected by the pitch of the sound and duration of the audio element. The direction of high pitch sounds is easier to detect than low pitch sounds; for example, the low sound of a ship fog horn seems to come from every direction, whereas the direction of a high pitched sound of a grasshopper is easy to detect. The tempo of the sound is also an important factor when providing instructions for moving; a fast tempo encourages to act, a slow tempo to stay put. A short-duration sound, for example, short clicks are better than long-duration sounds.

Cross-modality challenges a child to move

In his thesis, Jukka Jokiniemi structures accessibility with a fourfold model, where the sensory affordances of the environment and capacity of an individual determine the possibilities to access and act. The environments have been named Onnela (paradise), Aukio (square), Näyteikkuna (display window), and Selli (cell). In Onnela the individual's own readiness to act is good and the environment has plenty of accessible affordances. Aukio is an empty space where there are not enough usable affordances, even if the individual's own readiness to act is good. The situation can be corrected by adding cross-modal landmarks in the environment. In the case of Näyteikkuna, there are enough interesting landmarks, but the person's own readiness to move is not sufficient. This situation is remedied by increasing rehabilitation and the use of aids. In Selli both the affordances in the environment and the individual's readiness to act are limited.

"Interesting sensory affordances make the environment challenging. A cross-modal world also captures a small child's curiosity and makes them get up and go familiarise themself with their environment," says Jukka Jokiniemi.

"An environment stripped too clean is uninteresting to a child and does not stimulate any kind of independent activity. The environment must offer interesting new things for a child and an opportunity for uncompelled activity."

You can join the association, as a member or a supporting member, or you can subscribe to the Silmäterä magazine published in Finnish, by using the attached form. Fill in the form carefully and send it to the address Näkövammaiset lapset ry, Malminkaari 15 A, 00700 Helsinki. You can also join and subscribe over the phone +358 9 752 2540, by email nlt@silmatera.fi, or use the form at www.silmatera.fi.

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Service Form

☐ **I WILL JOIN AS A MEMBER**

Parents of a visually impaired child can join as a member. The annual membership fee is 15 euros per person, or 25 euros when two parents join. The membership fee includes the Silmäterä magazine in Finnish.

1. Name of the parent joining as a member

Phone number Email

2. Name of the parent joining as a member

Phone number Email

3. Name of the child with visual impairment and

date of birth *(the date of birth information is used to target the communication to different age groups)*

4. Address and zip code

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