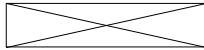


## *Our Journey With Our Son Jakob*



*Tamara & Jonas Himmelstrand*



Every parent wants the best for their children. Every child is special—so every journey with every child is special. Like all parents, we want to give our children the best possible start in life. Jakob, our first child, was born in 1994. He seemed to grow up normally, except for a deeply introverted expression. Slow in learning to talk, he was extremely sensitive to chaotic surroundings. As good parents, we listened, supported and tried to help our son. As time passed by, however, it was clear something was not right. Finally, at the age of 5, Jakob was diagnosed as having infantile autism, which is a severe mental handicap in communicating to others.

This is where our journey began. After being convinced that Jakob's difficulties were a form of autism, our family doctor referred us to specialists at the neuro-psychiatric clinic in Uppsala, Sweden. But the earliest appointment we could get was in 18 months! Time was of the essence, because we knew that it was vital to provide specialist help or training at an early age.

The first step was to pool our strengths. We both have extensive experience in training, teaching and personal development. Jonas is a consultant who encourages people to develop their talents and also passes-on skills they can use to become fine educators. Tamara is a violin teacher who has her own creative teaching method. Both self-starters, we put enormous energy into what we believe-in. Scanning the world for possibilities, we recalled reading about an autistic boy who was completely cured. The BBC had produced a

documentary about the method—the Son-Rise programme, based in America. So we went searching on the Internet.

Son-Rise is a perfect values-match to our own training experience. The approach focuses on respect, love and a positive and enthusiastic attitude—plus a very specific way of relating to the autistic child. *Son-Rise uses whatever motivation—strengths--the autistic child has to start to build communication.* (Later we discovered the method offered by our local hospital is an older approach based on behavioural therapy.) The realisation also hit us that, if we took the Son-Rise route, it would require intense daily training 6-10 hours a day, 7 days a week, for years. The decision was made in our hearts, however, and we committed ourselves to the journey with Jakob.

Calling the Son-Rise Institute in Massachusetts, we found them very helpful. This led to us ordering the 'start-up package': some books, an introduction to the Son-Rise methods and instructions on how to set-up the special play room. Jonas also enrolled for the next special training programme in two months time. Getting started immediately, we set-up the special playroom—but with all toys out of Jakob's reach. He needed to ask for anything he wanted—but everything was geared to success.

Our demands on his communication would never be higher than Jakob being able to get what he wanted with a little effort. The message to the child is: *"The more you communicate, the faster you get what you want. If you don't want to extend your communication, you get it anyway--because this is a friendly world. It just takes a little longer time."* We tried out the playroom and, when Jonas returned from the course in America, we would start the work in earnest. This was already an exciting project in which we could build on everybody's strengths.

Jakob has always had tremendous strengths. We began the Son-Rise programme in June 2000, when he was 5 years-old, and focused on his assets. He is happy, intelligent, visual and has great personal integrity. He will put effort into things he is highly motivated to do---and no energy whatsoever

into other tasks. He has always been perfectly physically healthy, has great posture and excellent balance. We aimed to build on these assets.

Jakob's challenges were his total lack of communication skills. When asked a question, he would simply echo the question back. Sometimes this could be quite funny. When going too far out into the water on a beach, we called: "Come back, Jakob". He would simply yell back: "Come back, Jakob," then continue his pursuit of the waves. He did not understand the concepts of 'I' or 'You'. Frequently referring to himself in the third person as 'Jakob', almost as if observing himself from outside. His most advanced statements would be: "Daddy, buy milk in shop for Jakob". Combined with the inability to differentiate between 'you' and 'I', he would say things like: "Mommy help you to wash you". He used standardised phrases to get his basics in life, often using questions as requests. For example: "Are you hungry?" meant, "I am hungry".

Communication was not easy, partly because of the almost total lack of eye-contact, which is typical of autistic children. There was no talk back and forth. Sometimes there was a request from Jakob, but he did not understand any request or question put to him. Encountering these challenges, therefore, he had never been able to play with other children--nor did he show interest in his two-year-old sister. But Jakob did talk. He could recite by memory books we had read for him--over and over again for hours, not changing one word. Another autistic trait is extreme sensitivity to many impressions. Within a few minutes visiting a noisy shop, for example, he would get totally out of control and quite literally climb the walls. Whenever we had visitors to the house, he would first see who was coming. Not responding to them, he would leave the room to be alone. So let's look at some of the stages on our journey.

### The magic of the special playroom

Jonas returned from the Son-Rise course in America in August 2000. Everything was ready to start—and the first whole day in the special playroom was magic. Every interaction immediately became easier and we connected

to our son on a whole new level. Leaving the room after 8 hours, Jakob had a tremendous radiance--as if we parents finally understood his needs. Within a few months he was smiling, which he had never really done before. Jakob began to use a pen to draw and write letters, which previously he had absolutely refused to try. Now there were short moments of play with his sister, Rebecka, and he began to answer questions. At Christmas he retold something he thought was funny from a Donald Duck cartoon. Encouraged by this enormous progress, it was clear the approach was succeeding, which gave us the energy to keep working.

***Finding volunteers, a public meeting  
and a radio interview***

Every journey brings challenges and ours were only just starting. We did not have the financial means to give-up our jobs and spend the required 6-10 hours a day in the special room, 7 days a week. Rebecka, our daughter, also needed her share of the family time, so we required help. The Son-Rise programme recommended setting-up a public lecture to recruit volunteers. Such people needed to be carefully selected, trained and coached, however, if their efforts were to bear fruit. And every parent is sensitive to who is going to play with their child in a confined space for 2-3 hours. Jonas set-up a lecture in Uppsala--marketing it through our network and an interview on the local radio station. Twenty-five people showed up, more than expected, and afterwards we seemed to have 3-5 interested volunteers. We were overjoyed.

Son-Rise is demanding on the volunteers. The level of energy, enthusiasm and excitement must be high. They must also be highly attentive. For example, they need to pick-up on the cues regarding when to join the child in an activity and when to lead. Understandably, volunteers can find it hard to give unstinting loving attention to somebody who refuses to communicate. After a few months all but one of our original volunteers had quit. So we approached a social worker: Could we get paid assistants to help? No, but we could get 20 hours per month 'baby-sitting', as a relief for us as parents. We needed people willing to train to be Son-Rise assistants, rather than baby-

sitters. So we invited the social worker to our house and presented the programme. Success: we received a letter providing funding for 24 hours a month. We needed 45 hours a week, but it was a start, so we gave the salary to our only volunteer, making her a paid assistant.

### ***More challenges—and solutions***

Now it was May 2001. Sweden is a country with many advantages, including a high standard of living for most people. Everybody recognises this must be paid for, which produces a high tax society. One area that is highly taxed, for example, is employing other people. Jonas contemplated trying to expand his business to cover the costs of employing assistants--but would need to at least triple his net income to pay for the 45 hours a week! Sweden is not a volunteer culture and the welfare system is expected to provide help in most cases. The Son-Rise method was little known in Sweden, however, and we had to persuade the local municipality of its merits. This would be difficult and did not play to our strengths.

So we threw ourselves back into practising Son-Rise. During the darkest hours we remembered the statement: "If you find no support, then use your own passion. Support will eventually show up, because passion inspires others." That became our mantra. During the following months we and our assistant gave Jakob as many hours of training as possible. September came and we lost our assistant, who returned to her studies. Jakob was out of control, not getting enough time in the room, and we felt desperate. Then a train of events were set in motion.

\* We learned of another Son-Rise family who had managed to convince the local government to get a solid amount of assistant hours. Hope returned.

\* Calling the social worker, we became more demanding, saying: "It can't be right that we have to do this all on our own in a high tax society. Besides, other people are getting this support." She listened and agreed. But it would be difficult,

because the decision must be made at the political level. She would, however, be willing to help.

\* Months passed. Calling her again, she said she was working on the case, but requested that we do not call again and disturb her. At home, we hired another volunteer, but they found the task/job/methodology too demanding.

\* We decided to do another passion push. Building on what we loved to do, we devised a schedule that, when both Jonas and Tamara were at home, gave Jakob six hours in the room every day. The schedule was extremely intricate and strenuous, being timed to the minute. But the pluses outweighed the minuses, compared with Jakob running around the house out of control.

\* The schedule worked. Jakob became more communicative and we maintained this timetable for two months. Then came a breakthrough.

A few days before Christmas 2001, Jonas was called to speak at a local government meeting. Despite being given only a few hours notice, he gave the speech of a lifetime. Explaining our schedule, he outlined Jakob's progress. The people seemed deeply touched by what they heard. The outcome was that we got paid assistance for 45 hours a week, our best ever Christmas present. So we sought the right people as assistants. Determined not to repeat our earlier mistakes, we told everybody the job was highly demanding. Twenty or so people showed interest and, after meetings and interviews, we settled on four. Son-Rise demands enormous energy, so 2-3 hours a day is the most you can ask from any individual. Several months of intensive work showed that three of them were up for the job. In fact, two of these are still with us today in November 2004.

Since the beginning of January 2002 we have successfully recruited more assistants. First, they must have a solid psyche to manage the job. Second, they must be encouraged and given great support during the initial training.

We start with 10 minutes in the playroom and a few simple instructions--then make extensive use of video feedback. Assistants who embrace the method increase the time slot until, after 4-6 weeks, they spend up to two hours in the room. Jonas, with his background in training, is in charge of the assistant's introduction. Tamara, with her one-to-one talent from violin training, then takes over. She meets every assistant to go through the video feedback once a week, which continues throughout their work with us.

Life goes on and running the programme calls for managing the household effectively. Jakob requires a diet free from gluten, casein, fast carbohydrates and additives. He cannot eat 70% of what is offered in the supermarket. Time is crucial—so preparing a meal can take no longer than 30 minutes, which makes the menu very Spartan. So Jonas, the logistics person, manages the shopping once a week through a custom-made list, which saves hours every month. Tamara, accustomed to timetables from being a violin teacher, maintains the schedule for the assistants, video feedback and 'team meetings'. Maintaining her violin education, she schedules all her pupils for the one day a week when Jonas is home. We keep this lifestyle throughout the year, except for three weeks every summer, when we go to the beautiful island of Gotland in the Baltic Sea. The creative chaos calls for everybody knowing the tasks and priorities. Jakob's progress, however, provides the positive energy that keeps it all together.

### ***Achievements along the journey***

The media had given us our first glimpse of Son-Rise, so we wanted to share our story with other people. In early 2002 we called our local newspaper and invited them to write about the programme. They produced two articles, one in February 2002, the other in June 2003. The same journalist wrote both articles--and was amazed at Jakob's progress between the two visits. Later, In early 2004, he was ready to attend a normal school class for between one and two hours a week. Now:

\* He can sit for 45 minutes among 23 other children and, when appropriate, be still and quiet.

\* He can raise his hand, answer questions, communicate his needs, express his feelings and his eye-contact has drastically improved.

\* His imagination is excellent. He can read, write and do maths—plus his English is superb. He has a passionate interest in cars, rides a horse and, demonstrating a fine ear for music, is teaching himself the piano.

Jakob is, above all, happy. He has retained his energy, joy and proud posture throughout the intense training programme, proving the deep humanistic roots of the Son-Rise method. He still has challenges: His communication can be clumsy and he is very obsessive about his interests.

Children in the school classroom were polite, but still a bit wary. So the teacher invited Jonas to talk to the class. The children listened and asked many questions. They were touched after realising the difficulties Jakob had been through during the last four years. The next time he and Tamara arrived the class was transformed. The teacher and children received Jakob differently, smiling and saying: “Hello.”

Today, in November 2004, we face another challenge. The local government is embarking on intensive cost cutting, threatening some of the assistant hours. The only way to maintain these is to appeal through the courts. Sticking to our strengths, we have found an attorney with experience of this particular Swedish law--The Law of Special Support—while we continue doing our Son-Rise programme and documenting our successes. Whatever the outcome of the appeal, we will find some form of solution. So what have we learned on the journey?

\* Follow your values. Overcoming obstacles takes a lot of energy, but we were doing something we really believed in, which provided us with great strength.

\* Look for alternatives. There are always options, somewhere in the world somebody has probably tried some way that works. If

not, then try inventing one yourself. Invest time in finding, or creating, as many options as possible.

\* Get visible results. Showing visible results has been one of the keys in getting continued support for our programme.

\* Passion is contagious. Passion and success inspires and attracts other interested people.

\* Behind every public official is a human being with a heart. No human being can resist love, joy and excitement for any length of time.

So the journey continues. And we are thankful for all the lessons along the way. But then, as we said at the beginning, every parent's journey with every child is special in its own way.

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*Tamara works as a violin teacher and also leads workshops for people who want to maximise their teaching skills. She has been passionate about teaching ever since giving her first recorder lesson at the age of 8. Whatever the activity, she builds on peoples' strengths by creating joy and success in the learning situation. Born and raised in Switzerland, she trained as a violinist and violin teacher at the Conservatoire in Lausanne, before moving to Paris where she trained as an actress. The concept of the inner violin sparked her interest in inner development and she devised an inner-motivated method for the arduous job of learning the violin. Parallel to her musical studies, she engaged in a four-year training programme in personal transformation. Combining her wide portfolio of skills, Tamara orchestrates a high quality training programme for her autistic son. In her spare time, she is working on a future book on motherhood. She can be reached at [tamara@thc.se](mailto:tamara@thc.se)*

*Jonas has worked as an educator, mentor and writer for the past 25 years. Based in Sweden, his work focuses on personal development, team development and enabling people to develop their skills as educators. He has had great impact, for example, in helping knowledge workers—such as*

*scientists, lawyers and other professionals—to communicate their messages in an inspiring way. Born and raised in Sweden, he spent two years in America, three years in Nigeria and, by the age of 16, had travelled around the world. His university studies included maths, chemistry and social-anthropology—but ultimately he found the chemistry between people more interesting than chemistry between molecules. Jonas has worked extensively in the private and public sector in Sweden as well as abroad. He has written three books and also publishes a bi-weekly newsletter, Strategies to Learn & Grow. He can be reached at [jonas@stratletter.com](mailto:jonas@stratletter.com)*

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