

Life would not be the same without you:

To be a family with two Aspies children

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This article is based on a presentation made for an autism seminar. The presentation has been based on my overall conception of the nature of autism and the experiences I have had with my children. I will not describe in detail the many characteristics also associated with autistic behaviour, for instance reduced gesture, fearlessness, rigidity, food problems.

My primary target groups are parents, friends and family, and Aspies. Secondary groups are professionals such as educators, teachers, psychologists, doctors, consultants and politicians.

I am the mother of 9-year old Nicolai who is Aspies, highly functional autistic with ADHD¹ and Tourette Syndrome and 5-year old Christian who is also Aspies with ADHD. Our life is very different from that of ordinary families and I would like to tell you about our family life. I will often refer to incidents with Nicolai as I have had the most experiences with him.

A strong but difficult life

Life with Nicolai and Christian has been rewarding but also difficult. We have many good, funny experiences. It is something special that we have been given the opportunity to be with persons who are thoroughly honest, for better or for worse. The children are without inhibition in their immediate anger and happiness. They can figure it out but they are not manipulative and are a good counter balance to our world and material values. Their spontaneity and their enthusiasm spread true happiness.

Life would not be the same without you, Nicolai – it just came out one day when for the fifth time in the course of two minutes he said he was hungry although he could see that I was already preparing his food. Of course, I regretted it the moment I had said it, but Nicolai perceived it positively. His eyes lit up when he said: ‘Do you really mean that, mum?’ Since then he has reverted to the incident several times.

No, it is not easy to be Nicolai and Christian, it is not easy to be their family – it is a mission in life to be their parents. It is like a perpetual training camp for all involved.

The invisible but complex disability

Nicolai and Christian’s disability is invisible which makes it difficult for all of us – even on more levels than one.

¹ ADHD: Attention-deficit/hyperactivity disorder

You cannot look at the children and see their disability. They enjoy socialising with other people and are usually happy and smiling. Rather active, I admit, but so are many other boys. This is where others wrongly believe they are 'normal' but wild boys.

Both Nicolai and Christian are better than most people are at a number of things. They have an incredible memory and are capable of reciting verbatim long passages from stories after only having listened to the story once. They have strong visual abilities and see all details. Nicolai has a photographic memory. He can examine an insect and then draw it in proper scale with the correct perspective and the right colours and markings.

The children can be deeply engrossed in a project, which interests them, e.g. cutting and pasting dinosaurs in cardboard. Right from the start, they both have a very concise idea of what the dinosaurs should look like, how many species there should be, in which environment they should live (Jurassic Park) and what the roles and capabilities the different dinosaurs should possess.

Nicolai and Christian are both creative, full of fantasy and build complex constructions in Duplo and Lego blocks. It is obvious that they think in forms, patterns, functions and details. This is a common characteristic of children with Aspies.

The children also possess a refined logic, a very specific way of thinking and a very high power of abstraction. When he was two years old, Nicolai looked at a plane and asked: 'Why does the plane not fall down?'

If Nicolai and Christian need an explanation, they will understand it immediately – except for a social context. For example, it was difficult for me to explain how a car motor works even though I was reading from a manual. Nicolai listened to my explanation and then retold the whole thing in a way so that I suddenly understood it. On the other hand, I can for the umpteenth time tell Nicolai to remember to flush the toilet, but to no avail.

Social and emotional problems

There are a number of things the children cannot do. Overall, they lack the intuition and the flair others are born with and constantly develop. Nicolai and Christian find it difficult to identify with other people's thoughts, actions and feelings, as they possess little empathy. They have difficulty understanding their own feelings, thoughts and actions, which causes many problems in approaching, communicating and interacting with other children and adults.

I am convinced that the children hold feelings such as joy, anger, sorrow, worry, enthusiasm etc. To a certain extent they are capable of (have learnt) to respect and show compassion for other people, but the children have difficulty in handling their feelings. At one time, I had to tell Nicolai to treat me as glass when he would hug me. His hugs were so strong that I was gasping for breath.

Apart from having difficulty in handling their feelings, the children also lack security in expressing their exact feelings. A few years back Nicolai would hug a frail elderly and a baby with the same intensity as he would me. Nicolai and Christian are not aware that they should grade their emotional expressions depending on the person receiving their affection. I am happy to say that they have learned to do so now.

Nicolai and Christian also have difficulty understanding that certain situations need a reaction from them. One day you will see them comforting a child who has hurt itself, the next day they will not. One day I asked Christian why he had not comforted a boy who had fallen. His response was 'But Troels didn't cry!'

If an outsider without knowledge of Christian's disability had watched the situation, he or she would easily have thought that Christian was insensitive and perhaps even lectured him on remembering to be a good friend to Troels. However, Christian is a good friend who always comforts a child if he can *see* or *hear* it *crying*. The crying is a prerequisite that elicits a reaction from Christian reacts. If Christian in the aforementioned situation receives criticism from an uninitiated adult, he will feel very sad and wronged because in Christian's opinion he *is* a good friend. This easily leads to breach of communication.

Communication problems

An example of how difficult it is for the children to read their surroundings is demonstrated when they do not understand that another child has stopped listening to them after they have talked about a favourite computer figure for 10 minutes, without letting the other child have a say. Once Nicolai and Christian have started a story, they cannot stop and relate to the others' comments but have to finish what they started. Otherwise, they will have to start all over again, with what they were going to say. This behaviour makes it difficult for them to develop relationships.

Their friends do not understand that the boys chatter and finally give up listening to them. Their friends do not want to hear all that chatter and often find other children to play with instead. As an adult, it is therefore important to listen to them and to be patient.

It is sad to note that this is how it is. As mentioned before, Nicolai and Christian have a social disability but are interested in contact with other people. Their way of talking about their interests is their way of trying to be social with other people. However, the children are not capable of creating contact so that a dialogue arises between them and their friends.

Compensation through copying

Both our children are incredibly good at copying other people's behaviour, speech and gesture. They are therefore to a certain extent capable of hiding or camouflaging their actual problems. By copying, they manage to compensate for the disability. Nevertheless, the disability remains and it may cause the children great distress as they copy without

discrimination. The children do in fact not possess a filter. I remember an episode with Nicolai when he was 4 years old. I will describe the incident as a story.

Misunderstanding

I am working at the computer checking e-mails.

Nicolai comes into the room saying 'Mummy'.

When I turn to find out what Nicolai wants, he says 'pruhhhh' with the intended result that I am sprayed with spit all over my face.

I get surprised and angry at being spat in the face and react in an angry voice saying 'That is really disgusting. Stop it.'

Nicolai, who had just seen this behaviour on the television and expected that I would find it funny, gets surprised by my reaction and reacts violently. He hits me on the head so my glasses fly to the floor; he screams and is angry to have been misunderstood.

I then take Nicolai into the bedroom and wrap a duvet around him. When Nicolai has calmed down, Nicolai and I talk about what went wrong and he is happy to be understood.

Nicolai would not react so violently today but I think the incident illustrates how difficult the children's world is. Being misunderstood and disciplined must cause the children so much fear, insecurity and frustration. Therefore, I greatly admire and respect the children's ability to constantly forgive their surroundings and then to the best of their ability try and learn 'normal' behaviour.

What Nicolai and Christian are capable of one day they may not be the next day. They do not store their experiences in their mind but learn through copying. It is difficult to assess what they have actually learned and what they have copied. The children also possess the ability and the will to 'want' to do certain things and they manage to stay focused. However, after some time they have used so much energy on controlling their behaviour that the surface cracks. You will then experience that they function well as 'normal' children one day but the next day they encounter problems due to tiredness etc.

Dysfunction of the brain

The children have difficulty processing sensory information in their brains. For example, voices, light, colours, noise, people, animals, buildings, vehicles and trees become jumbled in their minds – and cause them interruptions in the way they perceive information and experiences. An ordinary phone call causes disturbance in their soul. The children can play quietly and then only in a matter of minutes become distressed and tease each other. They cannot handle the disturbance and the sudden change in their daily routine.

Nicolai and Christian are also uncomfortable with going shopping, especially in shopping centres filled with colourful goods, people and music. When we go shopping with one of the children, we try to find a time when there are few people about and preferably a small shop without any background noise.

Since it is also difficult for the children to manage a change of scenery, we never take them on a shopping spree visiting many shops. We only go to one shop and the children are told beforehand that we are going shopping and which shop we are going to.

The need for peace, structure and support activities

We have to try to create peace in their brains and we can do that by ensuring strict structure, clearness and certain framework including regular resting periods. Nicolai and Christian are greatly dependent on this order and structure and they depend on adults to create this order and structure for them. They cannot do it for themselves – at least not as children.

If Nicolai and Christian are given structure and peaceful surroundings and if they have the support of an adult who can guide them and be ahead of them, they can often manage the demands that are put on them. This gives them incentive and energy to go on to new activities and break down their own limits.

If, however, Nicolai and Christian do not receive the framework their disability and special needs prescribe, they develop increased uneasiness, silliness, dwindling attention, lack of ability to concentrate and disrupted relationships. If they do not receive support, attention and are not met with understanding, their world will break down and their chaos will be channelled into a strongly hyperactive behaviour, fits of anger and breakdowns. The literature available on the subject also says that the children may end up with depressions and psychosis.

No matter how much support Nicolai and Christian may receive from us and their support environment, new difficult situations arise all the time and the children and we must relate to these situations. It could be situations like a favourite teacher stops at the school or mopping by the older children in the play ground, even that the ice cream parlour is closed by the time we get there– in addition to the whole world outside the protected environment.

How well Nicolai and Christian manage and will manage in the future depends on many conditions. As I see it, many issues are in play and they are in play in many different ways in a complex correlation. It is my experience that parents of children with autism should be extremely aware of which educational theory and practice are being used in the kindergarten and school and what framework and support are available. It is particularly important that early on correct action be taken in kindergarten and at school, as it will later have influence on the children's self-esteem and self-confidence. It is also important to maintain a rigid structure and as staff and parents to be very distinct in body language and information.

The invisible disability

It is difficult to have two children who look normal and behave normally in a number of areas. They are highly intelligent and capable of learning a number of things – and then, nevertheless, are disabled. It makes it particularly difficult as parents to have suitable expectations for the children and it makes it difficult for others to relate to the children.

Other people often misunderstand Nicolai and Christian's behaviour. If for instance they push to get a seat on the bus, it is not rudeness, as others may believe but a part of the disability. They cannot abide standing close to other people in a packed bus where they cannot see what is going on.

When they unconcernedly look for biscuits in other people's cupboards, it is not due to poor upbringing but because they are allowed to do so at home. It is therefore in their conception also perfectly all right to do so when they are guests. Until they have learned otherwise, they will undauntedly carry on with their behaviour.

Our work with Nicolai and Christian is also invisible. The more we are ahead and make corrections, the more we train with pictograms and social stories, the better Nicolai and Christian will function. This makes friends, family and even experienced psychologists say things such as 'There's nothing wrong with him' – 'You're just making him ill' – 'Other kids do that too' – 'He'll grow out of it'.

The disability influences the family relations

We know that they will not grow out of their disability. However, through training, praise and the right framework they can learn to compensate for the condition. Autism is hereditary and in many families, the effect of one child's disability and diagnosis can suddenly branch off to distant relatives. In many families, relatives may find it difficult to recognise or admit the children's disability.

Nicolai and Christian's disability is difficult to comprehend when you do not experience them continuously in every day life. As parents, we wish that family members would listen to us or borrow some literature at the library on the subjects of autism and ADHD. If there is no common understanding of the children's lifelong, reduced function ability, the conviviality between the children, their parents and grandparents will not work out on common grounds.

The phase of frustration and admittance

As parents, you go through many processes and phases following the birth of your child. As a baby, Nicolai did not sleep very much – two hours during the day at the most and he woke 3-4 times a night but we thought it was colic and hernia. When he was one year old, he was very active, incredibly happy and charming. 'Now that's a real boy', people used to say.

At 1½ years old, he knew all the car models and at two, he spoke fluently. Of course, we were proud of our clever boy. At 2 years old, he started in a nursery, which seemed to be

okay. The nursery was very structured, small and supervised by many adults. When he moved up to kindergarten (from 3 yrs), the problems started. He had conflicts with other children, shoved, hit and ran around.

At home, he took no notice of our instructions and fooled around or ran all over the place. We were very frustrated and did not understand – can he not or will he not do what we ask. What are we doing wrong, we asked ourselves. Finally, we realised that we had a problem we could not solve ourselves – we needed help.

When Nicolai was 4 years old, we contacted PPR² together with the kindergarten. Nicolai received support from an auxiliary remedial teacher and talks were initiated with the school psychologist.

Diagnosis phase

The diagnosis phase lasted more than two years and would most likely have lasted longer, had we not ourselves realised what was wrong with Nicolai. We waited and waited for a diagnosis. Only when you have one, you will have the correct approach to the child. It was a nerve-racking experience. Suddenly we were a case, a number of meetings were held with class teachers, the auxiliary remedial teacher and the school psychologist as well as the caseworker.

It was exhausting to prepare for the meetings, to participate in the meetings and to relate to the meeting afterwards. Always having to analyse, assess and relate to the things said about and the advice given about our child exhausted us. On top of that, we were assigned a school psychologist who had little knowledge of autism and who advised setting limits. One of his suggestions was to shout at Nicolai if he did something wrong. That is exactly what not to do, so we quickly stopped that practice.

It is, however, correct that we had problems setting limits to achieving a desired behaviour – our children are precisely children who do not absorb guidelines as so called ‘normal children’ do. Our children do not necessarily learn from their mistakes and cannot or find it very difficult to transfer learning from one situation to another. They do not store their experiences in their mind.

Insight

As mentioned earlier, after about 18 months we realised what could be wrong with Nicolai and started looking for information on autism, preferably something written by autistics so it would be easier for us to understand their world. Even though we experienced this insight as grief, it was also relief. However, we were concerned about Nicolai’s school in the Danish Folkeskole³, and the reading only made us wearier.

² PPR = Pædagogisk-psykologisk rådgivning [Advisory board for education and psychology, an advisory board established to advise civil services, schools and other institutions as well as parents and pupils/students.]

³ Primary and lower secondary school

School attendance

Nicolai started in a pre-school class with a full time auxiliary remedial teacher and I had to reduce my hours and only work part time. Later I had to take leave, as Nicolai could not handle staying on for the 'after-school activities' (SFO⁴). The municipality was not able offer a plan suitable for his situation and needs.

School was stressful and usually Nicolai was tired, frustrated and angry when he was picked up at 12.45 PM. There were too many children, too much noise and the wrong framework. Nicolai could not handle sitting in a circle close to other children for long. It was difficult for him during the breaks when there were no structure or clearness. He could not participate properly in the other children's play because he did and does not understand social interaction. He did not even understand when they were pulling his leg. He just smiled at them.

Nicolai and his auxiliary remedial teacher had no place of their own but had to sit in the hall. Further, his auxiliary remedial teacher was studying for a degree and was gone for several days so Nicolai spent time with several temporary teachers.

The auxiliary remedial teacher was a serious person so we had to ask her to remember to smile to Nicolai, otherwise he may think that she does not like him. We told her she was even allowed to overdo it, as Nicolai also has difficulties interpreting facial expressions. The same applies to Christian.

Awareness of the right framework, think long-term and general terms

Nicolai's difficulty at school suddenly made us very aware of how important the right framework is for him and ever since, we have been thinking long-term and in general terms. Despite Nicolai's problems, we experienced that he was well liked in his class, funny and imaginative as he is. We found out that he could manage to play for a couple of hours with one friend, so he often has friends coming to see him.

Self esteem – focus on possibilities and special abilities

It is good for Nicolai and Christian's self-esteem to visit friends and to have friends visiting. Nicolai once said that it really makes him happy to have friends visiting. Good and stable self-esteem is a prerequisite for accepting, getting to know and encompassing other people. Nicolai and Christian receive many hugs and much praise and they grow from it. Primarily, we look at their possibilities and abilities rather than their limitations. Not long ago the children had a playhouse and we let Nicolai explain the drawing to us, just as they both helped get the materials. They are both very quick to see the forms. Whenever we are having cake, they always decorate the cake and lay the table – they are very creative in that way.

⁴ SFO = Skolefritidsordning [After school care – an arrangement where children will be looked after by qualified adults between the hours of school and the time they are picked up by their parents]

Education/training

As previously mentioned, it is difficult to have expectations and set demands on Nicolai and Christian. Our experience has taught us to use our attention and intuition to read their behaviour and state of mind and then differentiate accordingly. We differentiate our expectations to the children based on their immediate state of mind and expected state of mind later. On their bad days, we do not ask them to choose a video to watch but select three and ask either Nicolai or Christian to pick one. We let them know that it is okay if they cannot choose and we will just find one for them. We do however try to convey 'We believe you can' and now that Nicolai is nearly 10 years old we set demands which he has to fulfil.

As parents, we also act silly or fool around and make mistakes so that Nicolai and Christian can see that nobody is perfect. We hope that this will particularly help Nicolai to downscale his demands to perfecting his drawings and school tasks.

Nicolai has several disabilities and it is difficult to live with, for him and for us. However, through understanding his world and with special training and aids, we can go far.

We could see that it was necessary to start with his actions, try to interpret them and adjust accordingly. It is a great responsibility as parents to take on when we, based on an action, have to interpret and some times say, 'Nicolai, you're sad because ...' But what is the alternative when he does not understand his own feelings and actions?

It can be hard to watch our children sitting fitfully at the table and fiddling with knives and forks. We cannot ask them to stop as you can 'normal' children because our children cannot do it because of their disability. Instead, we have to find other strategies. For example, we ask Nicolai and Christian to play 'I spy' and we have to guess what it is, or we take turns to make up a story. This will keep them occupied and they can easily eat in between.

As Nicolai and Christian are visual learners rather than auditory ones, we often visualise things. We may say, 'You have a short fuse, Nicolai – what will you do to stop the bomb from exploding?' Then Nicolai laughs and he actually succeeds in containing his anger.

From Boardmaker, a PC-program with pictograms (drawings), we print and laminate the drawings to make a day schedule for the children. As it is difficult for Nicolai and Christian to structure their tasks, we make a schedule for the various activities during the day. We stick the small drawings from Boardmaker on a board, and on a weekday, the morning will contain small drawings of what is going to happen that day. – Dressing, breakfast, brushing teeth, coats on, taxi, school and so on. It is up to one self how detailed the schedule should be. For a start, you can use simple pencil drawings and see how the child reacts to them. As time goes on the concept can be enhanced as needs develop.

We also make drawings of facial expressions showing feelings of pleasure, anger, weariness, surprise, sadness etc. When Nicolai and Christian have a particular feeling, we can show the face for that feeling and say, 'Now you're tired.' This way they can recognise the feeling.

We have combined this with feeling parameters so that the boys on a scale from 0 to 10 can show us whether they are only a little happy or very happy by pointing the arrow at a number.

We also do social stories. A social story is a story specially directed at Nicolai or Christian in a particular situation – a situation where the boys have problems. The situation is described from the boys' point of view and contains suggestions to solve the problem. A social story can be more or less complex but will often contain both text and pictograms.

We let the children rate the day with stars from zero to six when we chat after we have read a bedtime story to them. If Christian only rates the day to two stars, we can ask him why the day only deserves two stars. Christian can easily explain what has been bad that day. This gives us valuable information of his conception and we have an opportunity to make improvements adjusted to his needs.

Further, for each of the children we have created a book on boasting, practice and experience. Our goal is to give the children a better self-perception.

Parental role and responsibility

One of the most difficult things about being a parent is that you are 'on' all the time, day in and day out. When we are on holiday, we are not on holiday but have other experiences. It is difficult to go on a travelling holiday. One autumn we went to Samos – at the airport we were called to the gate twice but had to return to the lounge on both occasions. Nicolai was so confused and frustrated with the changes that he spent the entire flight on the floor below his tray.

When Nicolai has a difficult day, he is extra hyperactive, confused and rootless and has a 'short fuse'. On days like these, we constantly have to be ahead, make decisions for him, and ensure cosiness and diversion, to be the quiet counter balance.

On days like these, we have to say that we have tried this before and can manage. We must remember that we have ensured giving him the best framework we can supply and we know that he will be better – and his behaviour has improved after attending a special school.

The difficult balancing act

We find it a difficult balancing act to make allowances for all family members' needs. When Christian plays with his cars on the floor, Nicolai, who is very noise sensitive, can hear this and is bothered by the noise, no matter where in the house Christian is playing. How do you solve that problem so both children feel that justice has been done?

Furthermore, Nicolai seeks us out, and both children want to be on top of everything, which exhausts them.

Our solution has been to buy a weekend cottage. We inherited some money and found a small, cosy house where we can stay one adult with a child over the weekend or be together all four as needs be. The children enjoy swimming, being surrounded by the warm water, hearing the rush of the sea and collecting seaweed, stones and catching crabs. A serene peace comes over them when they are near the sea and we, the adults, can relax for a while.

Some psychologists say that having a disabled child does not mean that the family is disabled. There is some truth in that statement – if you understand it as the disabled and his needs must not always come first.

An limited life

It is true that if we as parents experience a deficit, we do not have the necessary surplus to handle the child. But as parents to a disabled child you have a limited life. As parents, we cannot lead a ‘normal’ social life and we both cannot work full time. We have to limit our own career goals to meet the need of our children. In addition, we cannot all go to the shopping centre or fairground together. It is difficult for us to keep up the house, garden and have time for each other and ourselves. Our needs must largely come second to those of the children.

The prognosis is that 80% of parents with disabled children get divorced, so if we are to stay together and preferably also have a long life, we shall as early as possible ensure some relief. It is a possibility that the municipality pays for a nanny for a number of hours each month, as it is also a possibility to let the children stay at a special institution or with a foster family every other weekend and for holidays. These options are a big relief.

As parents, we have to be aware that we need to do things with the children separately because the disabled child both influences and affects his surroundings. Christian thinks that Nicolai is the best and toughest big brother and copies his behaviour. This has caused Christian much more grief than necessary in his relations to other children.

Fortunately, during the past 6 months, Nicolai has become calmer and in addition, he is practising the behaviour he has learnt.

The public system

There is service legislation, which in principle gives the child access to special schooling, a possibility for covering loss of earnings through reduced work hours, covering additional expenses and to have relief, but the legislation is interpreted differently in the municipalities. It is a huge problem that no guidelines have been given on a uniform, common framework from the Ministry of Social Affairs. This means that as parents we have to spend hours and hours on formulating appeals on the decisions made by the municipality regarding our children.

In the case of Christian, the PPR2 in our municipality removed the 15 support hours (of which 13.0 hours were supervision) per week although the kindergarten personnel and we

pointed out that the work with Christian is far reaching and time consuming. Therefore, we had to seek a formal diagnosis from the Centre for Autism. The centre used the Autism Diagnostic Observation Scale to evaluate Christian. Although the results of the test showed that he has a pervasive developmental disorder, Christian did not receive any support for 7 months.

When Christian was awarded support again, the support had been cut in half and has been ever since, even though he now has an exact diagnosis. This has amongst other things led to me quitting my job and compensating for the lack of support by picking up Christian early from kindergarten every day.

The teachers at Christian's kindergarten do a great, responsible and competent work in relation to Christian but they have their limits with nine small children who need their presence. They are just as frustrated as we are that Christian does not thrive, as he should due to lack of support resources.

The level of hours for an auxiliary remedial teacher cannot be brought before the Social Board⁵ no matter what day care institutions and specialists say. It is a political decision made in the municipality what the level of service shall be. Therefore, I have written to the Minister for Social Affairs, Henriette Kjær, to draw to her attention the serious conditions which have weakened Christian's legal rights and quality of life, as our municipality has chosen to set a service level far below what is normal standard and educationally responsible. Further, I have contacted DUKH⁶ for counselling.

The parents are the only ones who think in wholes as regards the child, and I believe that it is necessary very quickly to make clear that you will have to work hard to secure the right framework for the child and good living conditions for the family. It is difficult to live with lack of understanding and support from the municipality. It is frustrating and lonely having to ask for help for one's child and to go through the experience of not receiving this help, which the child needs. Even though the municipality has a duty to advise us, this duty is neglected, and as parents we have to find our own way around the service legislation and with law in hand ask for various support facilities.

In addition to the problems with PPR2, we have experienced problems with overworked caseworkers with no insight to autism and who did not have the time or would not take the time to get familiar with the topic, who do not accept what the parents say and who do not understand – excuse the expression and metaphor – that even though the child is not sitting in a wheelchair it is carrying the wheelchair inside its head.

⁵ Det sociale Nævn [A county appeal board to handle appeals on decisions made in connection with social legislation]

⁶ DUKH – Den Uvildige Konsulentordning på Handicapområdet [A consultancy service for disabled persons which gives advice in individual cases]

Specialised teaching and support help

However, I can say that if you are prepared to do the hard work you can go far. When Nicolai was 3 years old, it took us all of one Christmas season to teach him to say ‘Yes, mum’, ‘Yes, dad’ when we called his name – but ever since he has responded that way every time we call him. When you experience success, it is a great victory for the children and us alike and the best motivator to tackle the communication difficulties, which always occur. Now that we know the children learn visually and not auditory we would have taught Nicolai the above much quicker by using pictograms and perhaps social stories/comic strips. Largely it helps to train and use specialised teaching tools.

Self-perception and self esteem

We have experienced that very early on Nicolai and Christian were aware that in some way they were different from other children.

In order to minimise the frustration of Aspies children and to make life easier for them and the parents I believe that you can talk to them about their disability as early as at the ages of 6 or 7 years. Our children have been very frustrated that they have not been able to fulfil the expectations of the surrounding world and they have not understood when they have not been able to do so.

Nicolai was clearly relieved when we told him that his ‘brain web’ did not function quite as it was supposed to and that was the reason why he had difficulties with some things. This self-perception/insight has given Nicolai a better self-esteem and great motivation for learning and training. He says, ‘There are things I can do much better than other people can and then there are things which I can’t do, but we can train so that I become almost as good at it as other people.’

As is seen from the previous sentence, life would not be the same without Nicolai who also has humour. First, I wrote Nicolai’s book by hand and I should write what he said – but he did not like my handwriting so I also had to write: ‘As you can see my mother has written a bit illegible – I simply speak so fast that she cannot keep up.’