

ALIX: A LITTLE GIRL WITH A BIG DISEASE



Valérie Gas and Sonia Montoya

The phenomenon of language thus occurs between two poles of silence. At one end is the muteness of one who knows nothing and can say nothing, whose main concern is to hide his lack of desire to communicate lest it betray his low humanization level. At the other end is the silent pinnacle of meditation of one whose power and refinement of language take him to the utmost heights of the word of man.

—Alfred Tomatis, *L'Oreille et le Langage*

Valérie Gas

Valérie is a clinical psychologist who was trained in the Tomatis® Method by Dr. Alfred Tomatis. She has spent over 20 years as a Tomatis® consultant, using all of the fields of application of the Method to help her clients. Valérie holds a DESS in psychopathology and a DESS in psychology and justice. She is also trained in systemic family therapy.

She worked on Dr. Tomatis's team for eight years before opening a Tomatis® center in Tours, France, which she ran for five years. Following this, she returned to Paris, where she managed the Tomatis® Children's Center for ten years. She is now living in Lorient, Brittany, where she has opened a new Tomatis® center and a center of systemic family therapy.

Valérie is a founding member of the International Association of Registered Certified Tomatis® Consultants, where she held the position of secretary until she was elected as vice-president in Dublin in 2009. She has been a member of the Tomatis training team for many years, and travels around Europe and the United States to train new professionals in both the Tomatis® Method and Solisten®.

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Sonia Montoya

Born in Colombia, Sonia relocated to France, where she studied developmental psychology at the University of Paris VIII, and linguistics and language acquisition at the University of La Sorbonne Paris IV between 1973 and 1984. She then went on to conduct research on epilepsy with dyspraxia in collaboration with Miss Leman, director of the psycho-pedagogical Valadon school. Sonia began developing her own method of teaching reading, writing and grammar in an effort to change the institutional approach to the study of school failure.

From 1990 to 1997 she worked with sick children at the Institut Curie, and between 1996 and 2009 she did a pedagogical follow-up of children with learning difficulties at the psycho-pedagogical center Tomatis® Écoute Communication in Paris. Her work takes a psycholinguistic perspective more involved in the development of language acquisition in children and in the process of professional self-efficacy.

CHAPTER 11

Alix: a little girl with a big disease

A CASE STUDY IN RETT SYNDROME

We met Alix for the first time at Écoute et Communication (the Paris Tomatis® Center for Children) when she was three years and ten months old. Alix's walking pattern was weak, looking almost "duck-like," and she had severe posture and balance problems. She had flat feet, walked on the outside of her feet and was very unstable, with a tendency to lean forwards. She was also unable to keep her head straight. She could mount stairs with the help of an adult, but could not descend them. She could touch objects, but could not hold them with her hands as she had almost no sensation of touch. And while she was a child who smiled frequently, she made no eye contact.

Alix also had a tendency toward self-mutilation, as was demonstrated by her banging her head and pulling her hair out. She was very sensitive to noise and would

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react fearfully to it. There was no verbal communication—although she would moan or laugh in an inappropriate way. She had a few ways of communicating non-verbally; she occasionally gave hugs and reacted to music and different pictures when she watched a videotape. She had a tendency to neither obey nor react to instructions.

Diagnosis

At the time of her arrival at our center, Alix had already been diagnosed with autism by the hospital. She was diagnosed with Rett syndrome one year and seven months after we first met. “Rett syndrome is a severe neuro-developmental encephalopathy that essentially affects girls and is characterized by a global deceleration in the psychomotor development followed by a loss in cognitive and motor skills. This occurs after a period of normal development.”¹

Alix was also diagnosed with trichotillomania (hair loss as a result of her continually pulling out her hair), digestive problems and sleeping problems due to bruxism (excessive clenching or grinding of the teeth). She was taking medication for epileptic attacks, was astigmatic and wore glasses. She was undergoing psychoanalysis to stimulate her language skills through play, which she particularly liked, and during the week she also attended a physiotherapy center.

Intervention

We decided at the onset of the treatment to limit her program to a total of 90 hours of Tomatis® training, spread over five sessions. The intervention plan consisted of a first session of 30 hours followed by four sessions of 15 hours. The intervention sessions were spaced at intervals

of four to six weeks.

We first used the Tomatis® stimulation with corporal and vestibular work. This enabled Alix to integrate her corporal image in order to later develop her gross and fine motor functions. The stimulation was equally aimed at boosting cortical energy, which provided Alix with more energy so she could find the drive necessary to advance, evolve, and fight her condition. In general, every acquired skill requires a certain amount of effort to obtain and sustain—even more so when one is also struggling with development. It is for this reason that even a small amount of increased energy can help in advancing a little further down the trajectory of development.

During the next stages of her intervention plan we focused on Alix's language and communication abilities. The Tomatis® training program combined with physiotherapy produced tremendous results for Alix. So much so that it was decided to continue working with her beyond the 90 hours that were initially planned—and in fact, we followed Alix for a period of eight years, on the basis of six Tomatis® training and physiotherapy intervention sessions per year. The physiotherapy portion of her program consisted of exercises in strengthening, orientation, spatialization, lateralization, and language stimulation (reading and listening to stories).

Results

The results started to appear very quickly. After the first session of 30 hours, Alix's mother started seeing improvements in her eye contact, communication, posture and muscle tone. The family decided to continue with Tomatis® training, as they observed changes with each intensive. Alix became quite calm, turning into a happy, warm and very affectionate young girl who needed a stimulatory and reassuring presence on a daily basis. She cooperated a great deal and her

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approach to various tests was reflective of growth. Her resistance to fatigue was quite improved, and her concentration capabilities became normal in a quiet environment. Alix became able to express herself through visual media and non-verbal gesturing, and memorized caregivers, objects, pictures, places and people. She also manifested adaptive skills and exhibited no affective problems. Her family environment continued to be a great support.

Alix improved in her ability to walk and exhibit motor control in a variety of activities. She also gained an improved understanding of herself, her body and her space-time environment. Once Alix started walking we introduced activities that promoted her ability to form a mental representation of her body, before continuing on to lateralization, spatial structure and, finally, temporal structure. This work required much effort on Alix's part, as we started with a general warm-up before commencing the exercises to enable the integration of various body parts and their position within space.

Today, Alix derives great pleasure from going for a walk. She has acquired the ability to grip items and is very aware of what is going on around her. We used books to stimulate language and enable her to express her feelings and

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respond in an appropriate manner to different affective stimulations. We also used poetry to work on her language rhythms.

Her sleep difficulties have improved, as have her digestive problems, and the trichotillomania has disappeared. However, the bruxism, although decreased, has not completely disappeared. She communicates more and more through visual and physical contact—she will come looking for you, will show her interest in something and tap you on the shoulder to make sure you understand her. She is capable of performing several actions in sequence to obtain something. She obeys and responds in a non-verbal manner to recommendations. She is very lively, full of energy and takes great joy in her life.

The work accomplished with Alix during these eight years—and the

incredible results she has achieved—only confirms our theory that the Tomatis® Method is an excellent way of supporting children in their development and their maturation (at the motor control, autonomy and communication levels). It is clear that, in cases such as Alix's, this method forms one of various necessary programs, with each separate group of listening training enabling gradual progress toward improving the wellbeing of Alix and her family.

But the essential element is having all professionals work together to support each child along their individual evolutionary path, and in a diagnosis as degenerative as Rett syndrome, this kind of progress has been truly amazing to watch.

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