

Synthesis of 25 years of life with an autistic child

[Social Life : Life Project] [Europe : France] [Témoignage]

Par Handiplanet le 02/10/2017

Mr. Filem Jomago, Dad of a young autistic man, traces 25 years of life, of hope, of struggles and of success...

Testimony of M. Filem Jomago

1992 - Jack is born and grows normally 18 months then the problems begin: the acquisition of language, food refusal, no acceptance of strangers to the family, maladjustment to life in nursery. Autism is diagnosed at 2 years old.

1995 - We are offered a ¾ h of sensory awakening weekly support! One of its parents must stop working to care for the nursery school refuse to accept it.

1996. the family goes on a mission in Africa where Jack will be integrated into the French nursery school, accompanied by an African nanny. Before leaving, I buy all the books of testimonies of people with autism that I find in the French language, to try to understand how it will evolve: I read all of these documents and begins to synthesize them, which will form the outline of a book.

1998 return to France, Jack between part-time nursery school in the neighborhood where he will "use" his teachers because its inertia is much stronger than their courage! It is supported at half-time in a day hospital where we will wait in vain, for 3 years, "the emergence of desire."

2000 - I'm being transferred to 700 km from the House but can't find a place for Jack before the beginning of the following year. So I have to live alone and I go back home every weekend.

2001 All the family finally arrives and Jack discovers the TEACCH method. He made rapid progress: sit a few minutes at a table, come eat at the restaurant, accept to be told 'no'!

2004 - Belgian psychiatrists of the SUSA come teach us families of the PECS and the TEACCH principle. We discover that Jack can sit and hold if he knows why it's done, how long it will last and what he has as a reward when completed. With a suitable Protocol, he can also accept the frustration of not having immediately what he wants, including her favorite treats: its weight stop climbing and finally stabilizes at a normal level for his age.

2007 - He integrates a SESSAD autism where the relationship parents-caregivers is privileged: team simply ask the parents what they want to focus for the current school year! For us, it's a revolution: he learns to eat anything else than of purees and he agrees to defecate in the toilet and not more in diapers pants. As a result, it will make spectacular progress.

2008 - I still have to change my place of work and go to 150 km from the House. Impossible to do every day trip: I still have to resolve myself to leave my family and go back home only the weekend.

2012 - on the occasion of registration of his little brother to the kindergarten of the village, the Director discovers that he has an autistic older brother and insists on accepting it in class. He will go for 3 years a few hours a week to sport and handicrafts courses, and will even be accepted in 6th grade but Academy inspector will oppose! It's terrible because it was a place of socialization for him and discovery of disability for its small (s) comrades.

2015 - After 3 years of efforts the SESSAD and family team period, Jack agrees Finally, at age 22, to go make his stool in the toilet and no longer in its age-old diaper. It opened the doors of a 'normal' support for the future: it can go long hours at the pool, indulge in the spa and the long hot baths, make long walks...

2017 after a carefully programmed change, Jack enters a residential home. For now, he is in day care, but he is supposed to stay in as a boarder when we can no longer take care of him.

And now?

Jack became a large forecastle of 1.75 m and 75 kg, happy to share his life between his family and his home: he gets up in the morning with a smile, he goes to the day care service with a smile, he's working with a smile, and he came back with a smile : who could tell more? Here is the summary of a slice of life of a quarter of a century with an autistic, a true, one who does not talk, screams and who types or claw as soon as he's upset, but we can manage without major problems. It is part of the majority of people with autism we'll ever see on a TV set because they are largely unmanageable, especially on condition of stress...

I kept reading all the evidence of autism and family that I found and I made a synthesis. This resulted in 2017 in the edition of a 440-page book titled "what dreams do people with autism have? I first selected 130 themes as diverse as food, sleep, education, games, sexuality, friendship, sport, illness, death, relationships with other children, with the family, caregivers, etc. Each theme compared the life of Jack to the autistic who testified of their and attempting interpretations of this composite if aberrant and incoherent in appearance, but so ritualized and predictable when we looks at it a bit.

Finally, a Compay Segundo proverb says that, before dying, do a child, write a book and plant a tree. Well, now I have to take care of the tree...

Filem JOMAGO

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