

Swiss Families and their Experience with ABA

Family 3

Our Personal Experience with ABA and Related Themes from the View of a Mother

Early Diagnosis

We were lucky that our son received his autism diagnosis relatively early. He was 4.5 years old and we still had time before school started to set up an intensive ABA program for him. Many parents in Switzerland receive the diagnosis later after the child is already placed in the special education school system. The child then already has a large deficit in skills in comparison to his peers in regular school. Some parents are unable to even receive an appropriate diagnosis for their child. The developmental problems are given a general diagnosis (not autism) and the child is placed in a special ed school and not treated appropriately.

An autism diagnosis can be made as early as 1.5 years old. We need professionals that understand what autism is and have the courage to send their patients to a specialist if they are uncertain or if they suspect autism.

Our experience with ergotherapists, speech therapists, and child psychologists were disappointing and not helpful. We lost valuable time waiting for a diagnosis and didn't receive useful answers to our questions from rather helpless and incompetent 'professionals'. This valuable time could and should have been used for effective therapy.

Most families eventually learn that the KJPD is known for its work with children with autism. Parents and professionals need to be informed that it is important to get every child who is not developing normally evaluated as soon as possible. A 4-6 month waiting list is too long.

ABA

It is a fact that more and more families in Switzerland are interested in ABA therapy or have already set up an ABA program for their child. We hear about it from other families, find out about it on the internet, and learn about the remarkable progress and success kids are making with ABA. But, unfortunately, we also hear of other families that had an evaluation at KJPD in Zurich and were not even told about ABA as a possible treatment option. We parents are disappointed when we hear of such stories. It is the job of the best known child psychiatric clinic to inform parents about the possibilities for help that an ABA therapy could provide. If the parents take the next step to set up a program or go a different way – it should be their informed decision.

Where to find ABA in Switzerland

At present (2005) it is only possible for just a few selected families who have the support of the Zurich KJPD to set up an ABA program. Other families have started ABA with the support of speech therapist Cordilia Derungs or Silvia Senn – who both

have years of ABA experience. An important goal would be to make this therapy with its proven and measurable success, available to all of those parents who feel their child could benefit and want to give it a try.

Switzerland needs more qualified ABA professionals who are able to construct, support, and supervise ABA services. We recognize that in the last few years the KJPD has made efforts to get psychologists trained and offer ABA programs using psychology students. Unfortunately the demand and need is much greater than what is offered.

Recognition by the IV (Disability Insurance)

Some families have spent a lot of time, energy, and legal fees trying to force the IV to pay for ABA services. If ABA will ever be recognized the KJPD needs to play a leading role. We should have a Swiss study proving the effectiveness of ABA. With well over 50 families working with ABA in Switzerland this should be an achievable goal.

Acceptance by Special Education Professionals

Parents that have successful ABA programs and send their child to regular school often need a school aide to help the integration be successful. Their experience is sobering. Often the usefulness of ABA is questioned and other methods are suggested or used in the school. Important time is lost, the child loses hard-earned gains, etc. I think it is important to inform and train these professionals about ABA and gain their acceptance to work with the parents constructively. The aides should be familiar with ABA and how best to further the child's cognitive and social goals.

There are still many Swiss professionals the think psychotherapy is a useful autism treatment.

The fact that it has been proven conclusively that it is not effective (besides being very expensive) should be common knowledge by now.

Number of Autism Cases in Switzerland

Worldwide the numbers of children being diagnosed with autism has increased to 1 in 166. The Swiss IV cannot give us any information on the numbers in Switzerland. The main Swiss center for autism information in Friburg also has no numbers. The special education schools are full and the KJPD is overwhelmed with people seeking diagnoses and services. Only when these numbers are publicized will the demand for services carry more weight. Our society can't afford more and more cases that demand early intensive services that they aren't receiving – the result of which is even more expensive life-long institutional services.

Recognition of co-existing health problems by the medical/psychiatric community

It is a fact that many children with autism also suffer health problems. Many have gut issues such as chronic constipation, diarrhea. Also many have reduced absorption of important nutrients and are chronically undernourished. Poor detoxification ability allows heavy metals to accumulate to dangerous levels. Vitamin, mineral, and fatty acid deficiencies are commonplace as are food allergies and intolerances. Many parents in our group have seen benefits from special diets, supplements, and closer

investigation of gut and immune system issues. Unfortunately many parents are given much false information by doctors who, for instance, often feel that diet has nothing to do with development and proclaim that autism is a brain disturbance that is basically untreatable. I think it is time that psychiatric clinics and the medical community accepts that the head is connected to the body and there is a need for a universal treatment concept.

Impfungen

Most of our parents believe the vaccinations have either caused or contributed to their child's autism. Our son had few immunizations which we feel is the reason he was not so strongly effected and improved his chance of recovery. Members of the Defeat Autism Now group demand a revision of the current vaccination schedule. The shots should not contain mercury, aluminium, formaldehyde, etc. At-risk children have a genetically reduced capacity to deal with these toxins and simultaneous live-viruses. In the future it will hopefully be possible to screen children before the shots and identify those who should have a different vaccination schedule.

We parents can't afford to wait for the studies that will prove the above. We should however have the possibility to find the information available and make informed decisions concerning our children's treatment. Autism is not hopeless. It is treatable.

Our Story

Our son recovered from autism. He attends the regular second grade without any assistance. He brings home good grades, meets school friends regularly after school, is invited to birthday parties, etc. He plays on a soccer team and is on the same level as the other kids. He attends the boy scouts with a friend and they also go to ski-camp together. He is a gracious, good-humored boy that is well-loved by the whole family.

We are thankful that we had an early diagnosis. We are happy that we were able to put together an ABA program and had the support of Dr. Gundelfinger. The biomedical treatment was another significant part in his improvement. We want to keep our story confidential, but we are more than happy to talk directly about our experience with other parents seeking help.