

CRC - Convention on the Rights of the Child

68th Session (12 Jan 2015 - 30 Jan 2015)

Review of Switzerland's reports, 68th Session, 12 - 30 January 2015

Switzerland's answers to the list of issues concerning the second, third and fourth periodic reports of Switzerland.

Autisme Genève's comments on Switzerland's answers to questions:

I.9, I.17, I.18, III.2 c and III.4

Question I.9

The Swiss authorities state that the practice known as "packing"¹ is neither recognized nor covered by social insurance (health insurance, disability insurance). This is clearly untrue as "packing" is practiced in public institutions, by the staff of said institutions. Therefore "packing" is automatically covered by social insurances (possibly without their knowledge?).

We are pleased to note that Switzerland formally recognizes the authority of the association *Autisme Suisse Romande* (of which we are a local chapter) regarding best practices in the field of autism. Insofar as the Swiss government agrees, in accordance with *Autisme Suisse Romande's* recommendations, that the practice known as "packing" is obsolete and constitutes **physical abuse**, it must be **prohibited**.

Question I.17

We note that Switzerland did not respond regarding the placement of children with disabilities in psychiatric units, nor concerning their parents being denied visitation rights.

We know of several cases in Geneva of children and adolescents with ASD being confined in psychiatric units, sometimes without the consent of their parents who are sometimes also denied access to their children. These children were medicated (psychotropic drugs), sometimes without their parents' consent, which has led in some cases to somatic and psychological after-effects. This is an extremely serious and urgent issue and we do not understand how the Swiss government could chose to ignore it.

1 Packing involves tightly wrapping a person's entire body, apart from the head, for up to an hour in wet icy cold sheets.

Question I.18

Switzerland states that the Cantons must ensure an education suited to the individual skills of all children and adolescents and that the aim of their education must be to help them become independent adults. However, there is no example of inclusive education for children or young people with ASD in Geneva, and even part time integration in mainstream settings is still a rare occurrence. With very few exceptions, children with ASD remain in separate special needs institutions, whose staff is mostly untrained in ASD and therefore unaware of the children's needs and where the curriculum is totally inadequate. In addition, the academic curriculum (when there is one) remains uncertified as long as the child is in special education (even part time). These children therefore have very little opportunity of attaining any kind of valid certification, which greatly diminishes their potential to become independent adults later on in life.

Therefore young people with ASD are doubly discriminated against:

1. They are not included in regular classes and very few benefit from even part-time integration.
2. In special education, separated from mainstream education, their academic skills are insufficiently developed and completely uncertified!

The Canton of Geneva cannot guarantee inclusion or even partial integration for children and young people with autism in mainstream schools, due to lack of an inclusive policy providing trained classroom assistants (shadows²) and specific training in ASD for teachers (mainstream and special needs³).

In Geneva segregation is the preferred option, as soon as a child is diagnosed with ASD, in violation of the inter cantonal agreement of the CDIP⁴. Parents are involved in the decision making process to place their child in institutional care, but they cannot choose to keep or enroll their child in a mainstream school. If they refuse placement in institutional care they have to keep their child at home and take care of his/her education on their own. We know a number of ASD children who are being home-

2 A shadow acts as an interpreter to assist the child when a need arises and stands back at other times to allow the child to experience as much independence as possible.

3 Mainstream teachers need to have a general knowledge of ASD and special needs teachers need to be trained in the different educational approaches to ASD (ESDM, TEACCH, ABA, PRT, PEC...) which is not yet the case in Geneva.

4 Conférence suisse des directeurs cantonaux de l'instruction publique (Swiss conference of cantonal Directors of public education).

schooled, and many more cases of parents having reluctantly accepted a special needs institution for their child, while knowing it to be inadequate, due to lack of resources for homeschooling or to pay for private schooling (both are very expensive and have to be entirely borne by the parents).

The only examples of inclusion of children and adolescents with ASD in mainstream education are in private schools, a blatant violation of the right to free education for all.

On November 15th 2014, as part of a scientific symposium organized by our association, the Geneva Department of Education officially presented their latest project for inclusion in mainstream schools: it is a special needs institution within the premises of a mainstream school, located in an aging residential area where the school no longer had enough pupils. In order to put the empty premises to use, a special needs institution was relocated in the school building. Two heads and their team and two systems coming from "two different worlds" were forced to collaborate, although everything in their organization, functioning, relationship with parents, learning plans, etc. was dissimilar. Ultimately, each section ended up working separately and the children with ASD remained in their own classrooms, which come under the special needs education system. As they were on the school premises however, they were given the opportunity to join in artistic activities in mainstream classrooms with their peers for a few hours a week. The first results of this new experiment were not disclosed, nor were the evaluation criteria; the conclusion given was that it would be desirable to have only one team in charge of both sections and "that at this stage it is more accurate to speak of intersection rather than inclusion".

It is quite obvious that this model is discriminatory and does not meet the academic and social needs of children with ASD. It is also disturbing that this project found its origin in a combination of circumstances (the need to put empty classrooms to use) rather than the needs of the children themselves. This kind of budget tinkering is a perfect illustration of the patchy vision that Geneva public authorities have of inclusive education, and their lack of planning of its implementation.

As for early and intensive intervention, the Assurance Invalidité (AI)⁵ doesn't cover the full cost of a child's attendance at the Centre d'intervention précoce en autisme (CIPA)⁶ of Geneva. Moreover, the CIPA can only accept **6 children**.

5 The Assurance Invalidité or AI is the federal social security for persons with disabilities.

6 Early Intervention Centre in Autism

Yet statistics show that:

- the prevalence of ASD is more than 1 in 100 (internationally recognized)
- there are 5,000 births a year in Geneva
- one can assume that 50 children a year are born with ASD
- one can assume that 30 of them will be diagnosed before the age of 3
- the duration of the CIPA's intervention is on average 2 years per child

therefore the CIPA should be able to accept not 6 children, but 60!

Early intervention is internationally recognized today as the most beneficial course of action for the cognitive and social development of children with ASD and to give them maximum opportunity for social inclusion and autonomy in later life. Early Intervention in autism is also by far the most cost-effective course of action for the State as it will save a substantial amount of expenses on special needs services and lifelong residential care; there is absolutely no excuse for the lack of funding of the CIPA.

Furthermore, Autisme Genève questions the need for a 5 year study of different intensive early intervention models which have already been validated by studies in many countries and are the subject of clear international recommendations. Do the Swiss authorities not know this? Pending the results of this 5 year project, hundreds of children in Switzerland are deprived of an early intensive intervention that could significantly change the course of their lives.

The Swiss authorities state that the AI pays for psychotherapy, even though it is not recommended for young people with ASD. ASD is not a psychosis, therefore psychotherapy is not only inappropriate, but in many cases detrimental to the child and his/her family. Would we prescribe cancer drugs to someone suffering from diabetes? The therapies recognized by the AI that are actually beneficial to young people with ASD, such as occupational therapy and speech therapy are not sufficiently covered. Paradoxically, the most effective interventions for the development of children with ASD (ABA, TEACCH, PRT, PECS, etc.) are not covered at all by social insurance.

Regarding the « allocation pour impotents »⁷ paid by the AI, the application form is completely unsuited to the characteristics of people with ASD, which makes it difficult to obtain this allowance. Furthermore, we would like to stress the outdated and insulting name given to this allowance. The AI does not inform parents that their child is entitled

7 The "allocation pour impotents mineurs" (allowance for impotent -meaning crippled- minors) is an allowance that is payable to any child with a disability, the amount of which varies according to the amount of help or supervision the child needs.

to it, which means many do not request and therefore do not receive it. The parents themselves must apply for it and when no one informs them (which is often the case) they have no way of knowing their child is entitled to financial help (what parent would consider their autistic child as a “cripple”?).

Question III.2 c

Switzerland does not reply about the number of children with behavioral problems receiving care from the mental health services.

Question III.4

Switzerland does not have statistics on the number of children with ASD or their situation.

Autisme Genève finds this lack of data extremely worrying because it means there is no supervisory body able to verify that young people with ASD live in conditions respectful of their rights. Moreover, in the absence of any statistics, no planning and anticipating of needs can be made by public authorities.

This lack of data and the "model" officially presented by the Geneva Department of Education (a special needs institution relocated inside a mainstream school which had empty classrooms to fill) show a total lack of political will to implement inclusive schooling. The Geneva Parliament confirmed this further on 19 December 2014 by rejecting a budget for inclusive education for 2015 and an amendment to include CHF 460'000 to hire classroom assistants for school integration (AIS)⁸.

As a result, the ASD children who will be leaving the Early Intervention Centre of Geneva in June 2015 will have no classroom assistant to help them in class and will be directed towards private schools. We have not been informed of where these children will be placed if their parents do not have the financial means to pay for a private school and assistant. We assume it will be a special needs institution, where the children will lose part of their acquired skills due to lack of cognitive and social stimulation. The long term financial expense for the State will be far greater than the 460'000 CHF requested to support these children in a mainstream class setting.

⁸ The AIS are classroom assistants who help special needs children in a mainstream classroom setting. There are at present less than 20 of them for the whole of Geneva Canton and none of them have received any ASD training.