Geneva, 25 April 2014

Joint submission to the Country Report Task Force of the Human Rights Committee (HRCtte)

LIST OF ISSUES ON FRANCE: "PACKING"

This is a joint submission by Autistic Minority International and Alliance Autiste.

Autistic Minority International, an NGO headquartered in Geneva, is the first and only autism self-advocacy organization active at the global political level, aiming to combat bias and prejudice and advance the interests of an estimated seventy million autistics, one percent of the world's population, at and through the United Nations, World Health Organization, and human rights treaty bodies.

Autistic Minority International is an associate member of the Conference of NGOs in Consultative Relationship with the United Nations (CoNGO) and a member of the NGO Forum for Health, a Geneva-based consortium of organizations committed to promoting human rights and quality care in global health.

Alliance Autiste is a French NGO run by and for autistics that aims to encourage and optimize cooperation between all civil society actors in the autism field in the country, be they local, regional, or national, individuals, self-advocacy groups, or organizations led by parents of autistic children. In addition, Alliance Autiste facilitates peer support and mutual aid among autistics, with regard to matters such as health, housing, education, and work, and strives to change public perception and serve as an intermediary between autistics and society at large, including political and administrative authorities.

We greatly appreciate the opportunity to be able to provide input for the list of issues on France (and the subsequent constructive dialogue with the State party), but will limit ourselves to discussing and stressing just one issue that has plagued the country for many decades, namely the abusive, degrading, and even torturous practice of "packing", that is, stripping autistic children and adolescents in psychiatric care naked or down to their underwear and wrapping them in freezing cold and wet towels and bed sheets or blankets for lengthy periods of time, either according to a fixed schedule, often several times a week, in order to effect behaviour modification or to calm them down when agitated.

By way of introduction, let us first emphasize that autistic self-advocacy is about more than patients’ or disability rights. Autism is a distinct culture and identity. The only one we know. Regardless of where in the world we live, autistics are more like each other than like the people surrounding us. Autism is a neurological difference that is both genetic and hereditary. There is no cure, and we do not believe that a cure will ever be found.
The autistic minority includes those diagnosed with Asperger's syndrome and various other conditions on the autism spectrum as well as those children and adults who remain undiagnosed.

In 2007, the United Nations General Assembly declared 2 April World Autism Awareness Day. On that day in 2013, UN Secretary-General Ban Ki-moon wrote: "This international attention is essential to address stigma, lack of awareness and inadequate support structures. Now is the time to work for a more inclusive society, highlight the talents of affected people and ensure opportunities for them to realize their potential."

In 2012, the United Nations General Assembly unanimously adopted resolution 67/82 "Addressing the socioeconomic needs of individuals, families and societies affected by autism spectrum disorders, developmental disorders and associated disabilities". In this resolution, the UN member states recognize "that the full enjoyment by persons with autism spectrum disorders [...] of their human rights and their full participation will result in significant advances in the social and economic development of societies and communities" and stress "the important contribution that non-governmental organizations and other civil society actors can make in promoting human rights for [...] all individuals with autism spectrum disorders [...] and their integration in societies". The GA voices its concern "that persons with autism spectrum disorders [...] continue to face barriers in their participation as equal members of society" and calls this "discrimination" and "a violation of the inherent dignity and worth of the human person".

As individuals and as a group, autistics continue to be denied the "four key pillars of minority rights", as identified by the UN's Independent Expert on Minority Issues, Ms Rita Izsák: "protection of existence and prevention of violence against minorities; promotion and protection of minority identity; equality and non-discrimination; and the right to effective participation in all areas of public, economic and social life".

Our very existence is in danger as long as autism, without regard to severity, continues to be viewed as something to be eradicated. Violence against us takes the form of behaviour modification, institutionalization, and abusive medical and therapeutic practices, such as electric shocks or "packing". Instead, we should be taught self-esteem, self-confidence, and how to advocate for ourselves. The autistic minority also includes those of us who hide their condition for fear of discrimination. This is no longer tenable at a time when millions of children diagnosed with autism come of age and many more get diagnosed as adults. Autism awareness must lead to acceptance, recognition, and respect for autistics. Only autism acceptance will ensure our full and equal participation in all areas of public, economic, and social life.

Article 7 of the International Covenant on Civil and Political Rights states: "No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment. In particular, no one shall be subjected without his free consent to medical or scientific experimentation."

We hold that the ongoing practices in France with regard to "packing" violate this article, particularly as recent pushes by the national health authorities to stop "packing" seem to

1 http://www.has-sante.fr/portail/upload/docs/application/pdf/2012-03/questions_reponses_vdef.pdf
have been circumvented by psychiatric institutions and facilities, for example by declaring "packing" an experimental practice and those autistic children and adolescents subjected to it participants in medical or scientific studies.

Fact is that "packing" has been thoroughly discredited by scientists in other countries, as evidenced by publications in leading medical journals, such as Laura Spinney's article "Therapy for autistic children causes outcry in France" in *The Lancet*. She writes: "In France, autistic children [...] routinely undergo a treatment that [...] many parents regard as cruel. [...] The therapy, called packing, involves wrapping a child tightly in wet sheets that have been placed in the refrigerator for up to an hour. When children are encased in this damp cocoon – with only their head left free – psychiatrically trained staff talk to them about their feelings. Typically, the treatment is repeated several times a week, and depending on the results and the severity of the child's condition, it can continue for months or even years. [...]"

"[T]here must be several hundred teams using it across the country. A day-case hospital in Bordeaux that used packing was the focus of a short documentary aired on French TV in April [2007], which provoked outrage from organisations representing parents of autistic children. [...] Autism France's [former] president, Mireille Lemahieu[,]... points to potential negative effects of the treatment, such as seizures and heart attacks, which could result from the thermal shock of being swaddled in icy sheets. She also points out that children who cannot speak – which accounts for most of the recipients of packing – cannot withhold their consent for a procedure that they do not enjoy. [...]"

"'It is a kind of aggression against somebody who cannot respond or defend themselves', commented one shocked French psychiatrist, who preferred to remain nameless, on learning that the 'old-fashioned' technique was still practised in France. She said that parents could be placed in a difficult position, because demand for places for autistic children at day hospitals or therapy centres often outstrips supply. 'Whether or not it is true, they may be afraid that by saying no, and opposing the doctor's recommendations, they will jeopardise their child's place'."

The article also mentions "the autistic author and scientist Temple Grandin [who] invented the 'hug machine' to give her the kind of pressure she liked, and [advocates of "packing"] cite her as evidence that packing is pleasant for autistic patients. The difference [...] is that Grandin could choose." Temple Grandin, a professor of animal sciences at Colorado State University, has distanced herself from "packing", though: "I would hate packing. The child should be able to control the pressure himself. The squeeze machine works on this principle. Packing would be useless and highly stressful for the child."

In 2011, a group of eighteen well-respected autism researchers published "Against Le Packing: A Consensus Statement" in the *Journal of the American Academy of Child & Adolescent Psychiatry*. They find: "This alleged therapy consists of wrapping the patient

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(wearing only underclothes or naked in the case of young children) several times a week during weeks or months in towels soaked in cold water (10°C to 15°C). The individual is wrapped with blankets to help the body warm up in a process lasting 45 minutes [...]. We have reached the consensus that practitioners and families around the world should consider this approach unethical. Furthermore, this 'therapy' ignores current knowledge about autism spectrum disorders; goes against evidence-based practice parameters and treatment guidelines published in the United States, Canada, United Kingdom, Spain, Italy, Hungary, and Australia; and, in our view, poses a risk of preventing these children and adolescents from accessing their basic human rights to health and education."

The degrading and torturous practice of "packing" is well-documented and has been condemned repeatedly and widely, by autistic self-advocates as much as by parents of autistic children and autism experts. Still, France has failed to outlaw it. Moreover, there is anecdotal evidence that "packing" is also used occasionally on non-autistic patients, such as children, adolescents, or adults diagnosed with psychosis, children or adolescents with anorexia or schizophrenia, and even elderly persons in psychiatric care.

Proposed question on article 7:

Please clarify the official position of the French State party on "packing". How widely is it still used, and when will the practice be prohibited wholly and completely, without exceptions and reservations? What steps are being taken in particular to make sure it does not continue in the guise of medical or scientific experimentation, and has any such research lacking free and informed consent of its subjects been awarded public funding?

Thank you for your consideration.

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