To the parliamentary committee
for the inquiry into the future of the Swedish
migration policy, (Ju2019:01)

“The political parties agree to push for a new ‘humanitarian ground for protection’ in the parliamentary committee.”

Asylum policy is toughening across Europe, and Sweden is no exception. Despite a good reputation with regards to a humane refugee reception there are many, and increasing numbers of cases in Sweden, that are worrying. To apply for asylum is a human right, and must be applied at all stages for refugees, asylum seekers and people living in hiding. *The Ethics Commission in Sweden (Etikkommissionen i Sverige)* specific purpose is to bear witness to, and raise awareness of, how human rights are applied or not applied in the asylum process.

Editors: Anita D’Orazio, Magnus Kihlbom and Christina Trapp Bolund

THE ETHICS COMMISSION IN SWEDEN,
NETWORK FOR HUMAN RIGHTS
IN THE ASYLUM PROCESS

**ETIKKOMMISSIONEN I SVERIGE,
NÄTVERK FÖR MÄNSKLIGA RÄTTIGHETER
I ASYLPROCESSEN**

This report was translated into English in December 2019 – January 2020 by Karin Johansson Blight, RGN, MSc Public Health, PhD Psychiatry. The ambition has been to stay as close as possible to the original report in Swedish. Thank you to Mr Andrew Blight for proof-reading the English translation.

To the parliamentary committee for the inquiry into the future of the Swedish migration policy, (Ju2019:01)

We, the signatories to this report[1], who for many years have assessed and treated asylum-seeking children, adults and families, welcome the January agreement's point 67: "The parties are in agreement about pushing for a new ground for humanitarian protection in the parliamentary committee".

Based on our experiences this is highly urgent. It is also clear from the fact that the United Nation's (UN) Convention on Refugees is based on the UN Declaration for Human Rights. The UN's Convention on Refugees is, in other words, the basis for a humanitarian and ethic-moral declaration.

This is further emphasised by the fact that the Convention on the Rights of the Child becomes law in Sweden in 2020.

This report aims to illustrate the need to reintroduce humanitarian reasons in asylum law and asylum case law, using concrete examples of acute humanitarian needs.

The report highlights vulnerable groups for whom humanitarian reasons for asylum are particularly poignant:

Children with grave functional impairments,
Children and youth with Resignation Syndrome,
Seriously ill persons (with cancer, need for dialysis due to chronic kidney disease) from countries where adequate health care is not accessible,
Plus, young unaccompanied minors and children with cultural attachment.

We would also like to ask the committee in their forthcoming work to make use of a reference group of psychologists and medical doctors from child- and adult psychiatry and child- and adult medicine.

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Eliot Wieslander General Secretary Doctors of the World Sweden

Josefin Öderyd, Solicitor, HS Law firm (HS Advokatbyrå)

[1] We are medical doctors, psychologists, volunteers and lawyers. Several of us are members of Doctors of the World Sweden (Läkare i Världen Sverige) and the Ethics Commission in Sweden (Etikkommissionen i Sverige).

Report Content

Humanitarian Reasons

What is "humanitarian reasons"?

The UN Convention on Refugees, the European Union (EU) and Swedish asylum law, are grounded in the UN Declaration on Human Rights. The Conventions for refugees are in other words humanitarian agreements.

Humanitarian reasons are according to the preparatory work to the former Alien's Act (UtlL.1993:398) of central importance to asylum law and in the general sense of justice.

The construct "humanitarian reasons" has not been defined. In Swedish texts the construct "humanitarian" refers to for example respect for human dignity and humanity. The British Cambridge Dictionary states that to be "humanitarian" is connected to improving human beings' lives and to reduce suffering.
The Swedish Migration Agency (Migrationsverket, MV) and the Migration Courts (Migrationsdomstolarna, MD) commonly appear to perceive humanitarian reasons as to mainly refer to medical circumstances.

The impact of subjectivity

Humanitarian reasons cannot be understood without considering subjective aspects[2]. The United Nations High Commissioner for Refugees (UNHCR) states that in order to assess the necessary conditions for the application of the Convention on Refugees' "well-founded fear", one has to take into account the asylum seeker's own appraisal of his/her situation, and personal experiences. In other words, everything which can serve to show that the prevailing motive is fear.

Many refugee families and individuals experience the thirteen months respite, which is provided under temporary leave to remain, as a time filled with a pressing fear for the coming deportation decision. Decisions on temporary leave to remain are in many cases not accepted as humanitarian reasons.

The concept of illness

The traditional Western illness model forms the basis for the medical certificates' common diagnoses in accordance with the International Classification of Disease (ICD) and the Diagnostic and Statistical Manual of Mental Disorders (DSM) manuals. These diagnoses are also the basis for the Swedish Migration Agency's (Migrationsverkets) and the Migration Courts' (Migrationsdomstolarnas) deliberations in asylum cases. This illness model has several flaws, including the explicit centring on the individual, which pose obstacles to the understanding that suffering can be a shared experience for several persons within a family group.

In particular, when it comes to psychiatric illnesses, which can be perceived differently between different cultures and countries. "There is a variation in expressions depending on, amongst other things, gender, culture and social context. The general phenomenon is described in DSM-5 and it is a vast challenge to multicultural psychiatric care."[3] In several countries psychiatric illness is taboo and shameful, and so are intellectual disabilities and dementia, and this increases fear of being expelled back to the country of residence ['home country'] both for the person who is ill and other family members.

Magnus Kihlbom

Humanitarian aspects with regards to cultural adaptation

There are, in other words, cultural aspects that are relevant to deportation in relation to psychiatric illness. Except for those, and humanitarian reasons on medical grounds, there are also humanitarian reasons due to cultural attachment.

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2 https://www.refworld.org.ru/cgi-bin/textis/vtx/rwmain/opendocpdf.pdf?reldoc=y&docid=56baf61a4

3 Sofie Bäärnhielm, Consultant at Stockholm County Council (Stockholms Läns Landsting, SLL) and Karolinska Institutet's (KI) Transkulturellt Centrum [In English: "Transcultural Centre"], and author of the book (in Swedish) "Transkulturell psykiatri: kliniska riktlinjer för utredning och behandling" [In English: "Transcultural psychiatry: clinical guidance for assessment and treatment"].

Children and youth, who have lived in Sweden for so long that they have gone through their entire schooling in Sweden, perceive themselves to be and are perceived by others, as Swedish. They would be regarded as foreigners if they were returned to their parents' countries of origin. Their parents have lived in Sweden as asylum seekers, as labour migrants and sometimes as refugees in hiding. Many articles in the media concern schoolmates and neighbours who are standing up for these refugees. For teenagers in their late teens, cultural attachment has contributed to the Swedish Migration Agency (Migrationsverket) granting asylum with respect to the European Convention, Article 8, which concerns the right to a private life in the country where one feels at home.

It can also concern youth who have come to Sweden as unaccompanied refugee children before November 2015. For example, youth who have grown up in Afghanistan or Iran with Afghani parents without citizenship in either Afghanistan or Iran. They have been taken care of by Swedish families and have been through all their school years in Sweden. In 2018, many of them were threatened by deportation, which led to a storm of protest amongst many people in Sweden, who had "opened their hearts" and their homes. The debate led to a temporary law, the so called "high school law" (Gymnasielagen) for people who due to their prolonged treatment of their asylum case had come further in their education and in their cultural adaptation. For the temporary leave to remain to become permanent the humanitarian reasons are heavily weighted. The humanitarian aspects of this is developed further in the article in the social policy journal "Socialpolitik no. 2/19".

Christina Trapp

How has "humanitarian reasons" been used in Swedish law?

The construct was introduced explicitly in Swedish asylum law in 1980. However, it had been applied in case law before that. *"Contrary to the demands of humanity"* has sometimes been used as a synonym. The term "humanitarian reasons" has sometimes been used together with imprecise descriptions of illness and needs of care: disability, illness, serious disease, illness requiring treatment, suicide risk, circumstances of exceptional humanitarian kind, etc.

In hindsight, how lawyers, the Swedish Government and Parliament have perceived "humanitarian reasons" (Humanitära Skäl, HS) during recent decades are evident under three themes:

1. The difficulty with the legal application of "humanitarian reasons".
2. The tension between on the one hand the humanitarian aims of the refugee Conventions and on the other hand the domestic politics and socio-economic strive to limit asylum immigration.
3. The large space that both the legislation and principle of proportionality (proportionalitetsprincipen) leave open for case workers' and lawyers' interpretation and "overall assessment" (samlad bedömning).

The Alien's Act changed for children 1 July 2014.

By this time, it was decided that it would be enough with "particularly aggravating circumstances" (särskilt ömmande omständigheter) instead of "particularly distressing circumstances" (synnerligen ömmande omständigheter).

The rules around impediments to enforcement were also changed so that children can be granted residence permits on the basis of medical impediments to enforcement or for other particular reasons, even if the circumstances are not of the same severity or weight as would be needed to grant a permit for adult persons. The example given was that in the preparatory work a circumstance that could result in a residence permit being granted was if the "child is suffering from a serious illness, which arises from or deteriorates after a rejection or expulsion decision, and when it is unclear if the child can have access to health care in the country of residence ['home country']", see proposition 2013/14:216. These changes aimed to "additionally promote the Rights of the Child perspective and focus on the best interest of the child".

Since the implementation of the law 2016:752 regarding temporary limitations to the possibility of being granted residency in Sweden, *the possibility of being granted a residence permit due to particularly aggravating circumstances is limited. Now such permits can only be granted if it would be contrary to a Swedish Convention obligation to reject or expel the asylum seeker.*

The thirteen-month time limited residencies have, through this, become a primary rule. Permanent residencies for children, which invoke particularly aggravating circumstances, are now only granted if it is found through an overall assessment of the child's situation that there are particularly distressing circumstances of a kind that they would lead to such a lasting reduced health condition in the child that it is absolutely necessary that he or she is granted permanent residency.

Josefin Öderyd, HS Law Firm

The Convention on the Rights of the Child, Extract[4]

Article 1 A child – means every human being below the age of 18 years.

Article 3 The best interests of the child shall be a primary consideration.

Article 4 With regard to economic, social and cultural rights, States Parties shall undertake such measures to the maximum extent of their available resources and, where needed, within the framework of international co-operation.

Article 9 A child shall not be separated from his or her parents against their will, except when that is for the best interests of the child.

Article 10 Applications by families who want to enter or leave a State Party for the purpose of family reunification shall be dealt with in a positive, humane and expeditious manner.

Article 12-15 The child has the right to express his or her own views freely in all manners affecting the child. When courts and authorities deal with cases affecting the child, the child should be heard, and the best interest of the child should be a primary consideration.

Article 22 The refugee child has the right to protection and help if it is unaccompanied or together with parents or any other person.

Article 23 All children with physical or mental disabilities have the right to a full and decent life in conditions which facilitate the child's active participation in the community.

Article 39 Children who have been the victim of abuse, exploitation, or neglect, torture, armed conflict or other form of inhuman treatment have the right to rehabilitation and social reintegration.

Article 43-45 Provisions on how all countries which have acceded to the Convention shall work to implement it. A UN monitoring committee reviews the reports of the States Parties. UN agencies and NGOs can also participate with information to the UN.

Article 46-54 Rules on how States can accede to the Convention and when it becomes effective. A reservation which is contrary to the aim and purpose of this Convention shall not be permitted.

[4] Sources: The United Nations Convention on the Rights of the Child and Save the Children (Rädda Barnen): "The Convention on the Rights of the Child in Brief" ("Barnkonventionen i korthet").

Background: Resignation Syndrome

Nearly twenty years ago attention was brought to the fact that within the asylum-seeking children population in Sweden, one group was notably increasing in Sweden. This was a group of children and youth who had stopped eating and drinking and who fell into stupors. They were called “apathetic” or “devitalised” children. When it turned out that the children were suffering from a condition that is life threatening, the diagnosis “Resignation Syndrome” was introduced. The National Board of Health and Welfare (Socialstyrelsen) published an information leaflet in 2005, which was later withdrawn. In 2014 the National Board of Health and Welfare (Socialstyrelsen) introduced Resignation Syndrome as a medical diagnosis in the Swedish ICD-system. From that point the incidence and clinical illness progression of Resignation Syndrome can be studied. In 2017 there were more than 100 children with a Resignation Syndrome diagnosis in Sweden. Resignation Syndrome is also described in other countries but to a lesser extent.

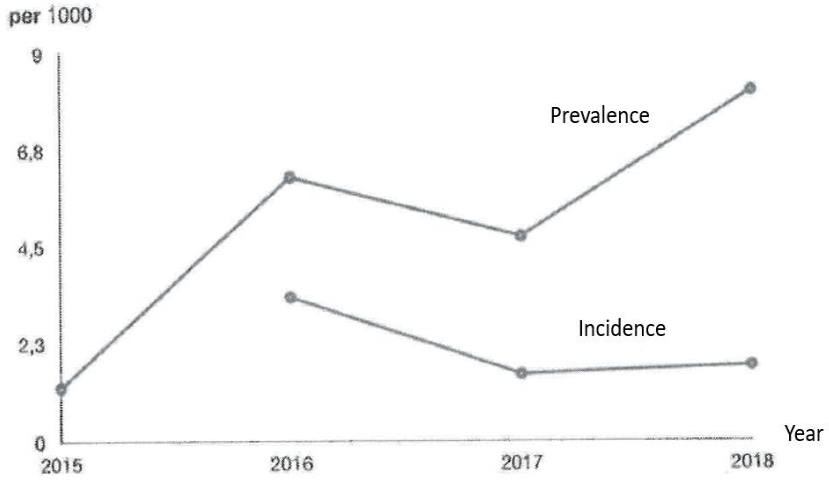
Clinical picture
Children with Resignation Syndrome look as if they are calmly sleeping but they are not sleeping! Children with this condition often have a raised pulse and high blood pressure, which are signs of stress. If this condition is long-lasting it becomes a strain on the heart and blood vessels with an increased risk of illness and death from for example cardiac arrest, stroke and arrythmias, even after recovery.

In its most severe form, Resignation Syndrome means that it is not possible to communicate with the children. They do not react to physical signals such as noise, cold temperature or pain. The children are not able to respond to their own body’s signals either, for example, they do not respond to the need to urinate or defaecate. Since these children are unable to swallow food or liquids, fluids and nutrition must be given to them so that they do not die. The best way to do so is through a nasogastric tube through which nutrition and fluids that are necessary for survival can be given. Since children with this condition are completely lethargic and do not move at all, it is necessary to prevent muscle and joint stiffness (contracture). This is done daily through passive movements. This treatment and care do not cure the children from their illness but is a life support intervention.

Illness progress
The children can lay in this life-threatening condition for years. If the safety of the family is improved, often through a residence permit, this helps to turn around the condition towards recovery. The family’s sense of safety cures the condition. Recovery takes time: on average it takes three months before the first signs of recovery can be observed. After that it takes another couple of months before the children are able to stand on their feet, can start to walk shorter distances and talk. After a year most of the children have not yet completely recovered. They suffer from concentration difficulties, which is notable as school achievements do not reach the levels that were reached before the onset of the illness. Many of the children are still severely depressed and can suffer from suicidal thoughts. It takes a long time before the muscles have regained their strength, which leads to pain in legs and the back.

Children who were granted permanent residence permits prior to 2016, recovered faster than children who have been granted residence permits in later years. The feelings of unsafety reoccur after a year when it is time to apply for asylum again, and this appears to prolong recuperation and recovery.

Children 0-17 with Resignation Syndrome per
1000 asylum seeking children



Resignation Syndrome, incidence (the number of new cases per year)

2016: Boys: 18 Girls: 18 Total: 36 (3,3:1.000)

2017: Boys: 12 Girls: 1 Total: 13 (1,5: 1.000)

2018: Boys: 0 Girls: 11 Total: 11 (1,7: 1.000)

Resignation Syndrome, prevalence (the number of existing cases, incl. children who remain ill and who have been registered previous years)

2015: Boys: 36 Girls: 47 Total: 83 (1,2:1.000)

2016: Boys: 34 Girls: 32 Total: 66 (6,1:1.000)

2017: Boys: 24 Girls: 16 Total: 40 (4,7: 1.000)

2018: Boys: 21 Girls: 30 Total: 51 (8,1: 1.000)

Anne-Liis von Knorring, Professor Emerita

Comments on the Temporary Law with Respect to Children with Resignation Syndrome; experiences from the "Care Chain for Children with Resignation Syndrome in the Stockholm Region" (Vårdkedjan för Barn med Uppgivenhetssyndrom i Region Stockholm).

In Stockholm in April 2019 there are eleven children with Resignation Syndrome who are being cared for jointly by Paediatric clinics and Child and Adolescent Psychiatry (BUP). Nine of these children still remain in a stuporous state and require nasogastric tube feeding.

Since the introduction of the temporary laws, the duration of illness has been extended. These nine children have so far, a duration of illness of 21 months on average (between 9-39 months), which is a considerably longer illness duration than before. Four of the nine children have ongoing temporary leave to remain, five are awaiting decisions on their applications. This can be compared with earlier data published in 2009 (Acta Paediatrica, Aronsson et al), where in 2005-2007 29 children had a total time of care, from onset of illness to recovery, of, on average, 12.6 months. During 2014 (data from the "Vårdkedjan i Stockholm") 12 children recovered with a duration of treatment of on average 16.6 months. Permanent residency was the most important factor to the turning point with signs of communication and regaining of function. The time of rehabilitation from first signs of contact was on average around 5 months.
Through our clinical work at the" Vårdkedjan för Barn med Uppgivenhetssyndrom" we have observed the following consequences:
Some of the children have recovered but it has taken a longer time than when children with Resignation Syndrome were granted permanent residencies. **The time of waiting for a decision on residency has been extended.** Rehabilitation has become longer, and the recovery is slower. It takes longer until the children open their eyes and make contact. It also takes longer before the children can eat and drink on their own and before they start to regain mobility.

Some children have not shown any indications of improvement after 13 months with temporary leave to remain but remain in a condition of resignation without any signs of recovery. We interpret this to be that the temporary leave to remain does not offer the type of safety and hope for the future that is necessary for the child to recover. The longer the duration of illness, the longer it takes to reach the turning point of recovery, and the larger the needs become for rehabilitation during the recovery phase. The children lose a large proportion of their upbringing, which can have a negative impact on their psychosocial development.

The children who have recovered are often vulnerable to new stress. They experience other psychiatric symptoms, depression, severe anxiety, and more or less serious suicidal thoughts. It is difficult for many parents to understand the new juridical process and they no longer have access to legal counsel after they have been granted temporary leave to remain. This means that the families suddenly are in a situation where they, themselves, have to submit a new application when it comes to impediment to enforcement.
In the longer perspective we also believe that the temporary law can have the following implications:
* The international literature highlights asylum systems, which are based on children with psychiatric problems not being provided with the prerequisites for treatment and recovery. Children and parents are living for several years with severe psychiatric symptoms and in fear of deportation, which is difficult to impact on using psychiatric treatment interventions.
* Every new re-examination of previous temporary leave to remain, can contribute to psychiatric symptoms worsening. This can contribute to children who have shown signs of recovery from Resignation Syndrome falling ill again and to children with psychiatric problems who have not experienced Resignation Syndrome in the past starting to show signs of Resignation Syndrome if they are met with a deportation decision, or as a consequence to the increased stress that a new decision entails.
* There is a high risk that families are subjected to severe social stress because where responsibility lies, between the Swedish Migration Agency and the County Councils/Municipalities parties, can shift rapidly. This means that the County Council/Municipality are no longer responsible for the family's housing and they can be forced to move to another place. The move for families from person identification numbers (personnummer) to "Swedish Reception of Asylum Seekers' Act numbers" (Lagen om mottagande av asylsökande, LMA. nummer), can also create difficulties in follow-ups to the families' treatment needs.

Mikael Billing, Psychologist *Bodil Schiller, Paediatrician*

Background: Yazidi People

The Yazidi population is a religious group of people with its roots in pre-Christian times. Ethnically, Yazidi people are Kurdish, and they commonly speak “kurmanji”, a Northern Kurdish language. Their belief system is monotheistic. God created from his light seven angels of which one, Malek Tawus “The Peacock Angel”, is the most important.

History

During early Christianity, people were missionaries in an area which was inhabited by Yazidi people; Armenia for example, became Christian already in 300 AD. In the 600s a militant mission evolved into “the holy war” with Islam. Yazidi people were considered devil worshippers and they were persecuted from all around. Yazidi people could/can be raped, enslaved, killed or subjected to torture or be forced to convert to Sunni Islam with impunity. Large parts of what later became the Ottoman Empire were forced to convert and the Yazidi religion remained only in isolated villages. During the Ottoman Empire rule, from the 1300s to the first world war, 72 massacres against the Yazidi population have been documented. For the “Islamic State” jihadi’s, the Yazidi people are as unfaithful and despicable as Christian people, and this was the reason behind the most recently known massacres taking place in July/August 2014.

Yazidi culture

In order to protect their culture/religion the religious leaders of the Yazidi people are still recommending today that children should not attend school, since the risk of being forced to convert to Islam is so great.

In many Yazidi societies the honour culture is pronounced. A woman who has been “touched” by a man of another religion is no longer considered to be Yazidi and should either be killed by her relatives or be ostracised from the group. This is relevant today in that Yazidi women who are liberated from IS imprisonment, have rarely been accepted for return by their families, especially not with new children.

Yazidi people have different status within their countries of origin. They are often not registered formally. They often give birth at home and for that reason they do not have any Birth Certificates. Since they have been forced to migrate across country borders to escape persecution by the surrounding or their own families, they have continued to live undocumented and hidden in the new country of arrival.

Yazidi people in Europe

Many Yazidi people’s lives have been saved in the last decade through the granting of asylum in Europe. One million Yazidi people are said to live in Germany. In Sweden there are around 6000. Yazidi people in Sweden are considered as Kurdish people.

Many Yazidi people came to Sweden in 2009 to 2010 before the war in Syria started. They had no proof of identity (ID) and could for that reason not be granted residency. However, nor could they be deported once the war in Syria had started. They arrived with small children who had to live in a constantly unsafe situation in Sweden; first whilst awaiting residency, after that with speedy rejections, and after that whilst waiting again in “limbo” without safety, and with reduced daily allowances. The parents have not been permitted to work or to learn Swedish, however, the children have been permitted to attend school. After four years the families have been able to apply for asylum again. The new application for asylum has often also led to rejection. This time around, when the new rejection decisions have arrived, their children have been in Sweden for many years and have “assimilated/become Swedish”, have friends, have had their whole education in Sweden, and participated in youth activities such as sports etc. These children have also become aware of how unsafe their situation is, in particular since they have been used as interpreters both by their parents and by authorities.

Resignation Syndrome amongst Yazidi youth
When the massacre of Yazidi people in Iraq took place in 2014, IS sent substantial material via YouTube so that everyone could see how Yazidi people were executed, tortured and how women were being sold as slaves. Most of the Yazidi children in Sweden saw these horrible actions, even if their parents tried to protect them from this by forbidding them to access the Internet. A number of teenagers could no longer stand the situation but started to show symptoms of Resignation Syndrome, as earlier traumas from the country of residence ['home country'] were re-activated and the hope for the future no longer seemed to be there.

Of the families with children with Resignation Syndrome, who were in their asylum process for a second time and had submitted their applications before 24 November 2015, all were given permanent residency (permanent uppehållstillstånd, PUT). Those families who were given the opportunity to apply for asylum a second time at a later stage, have at best been given temporary leave to remain (temporärt uppehållstillstånd, TUT) for 13 months. A small number of the children's condition improved during these 13 months, but they have not fully recovered. The majority of the Yazidi youth with Resignation Syndrome are still in a stuporous state since more than 3 years back under a continuous threat of deportation.

Can youth with Resignation Syndrome access care in their countries of origin?
All Yazidi people that we have met have been cattle farmers in their countries of origin, in Syria, Armenia, Russia and Turkey. It would not be possible to access health care in any of these countries for a child/youth with Resignation Syndrome, as the families' cultural circumstances involve nomadic living for half of the year.
The children would then have to be left to be cared for in institutions where there are no facilities available for nasogastric tube feeding or other treatment. In those cases, where honour culture is a reason behind the forced migration to Sweden, the risk for being subjected to ongoing violence is as high as before.

A Humanitarian Act of law is necessary in order to save these most vulnerable children's lives.

Elisabeth Hultcrantz, Senior Professor, Linköping University
Anne-Liis von Knorring, Professor Emerita, Uppsala University
Nemam Ghafoury, Medical Doctor, MD MSc CEO Dyna CompAB, JHK Clinic, Bajed Kandela Camp.

Case Presentations Resignation Syndrome

Case 1 D. 11-year old Yazidi boy

Background

Brought up in an extended family in a village in Syria. Since the war started there had been a constant worry within the extended family. The father's brother, at the time 29 years of age, was murdered by ISIS in 2011, since he did not want to hand over the sheep that ISIS demanded. The boy's family fled to Turkey, by foot, together with the whole village. The grandparents all remained in the refugee camp in Turkey. He lost all contact with them when the family travelled by bus and airplane to Sweden.

Situation in Sweden

The family applied for asylum on 13/1/2013, which was followed by three speedy rejection decisions, until November 2013. The boy has been crying at all the meetings about return and when the letter came from the Swedish Migration Agency: "they want to send us home". They lived in hiding and were searched for by the police to be deported. In August 2014, Yazidi people in Iraq were subjected to genocide. D saw this on TV and had also been playing computer games where ISIS was hunting and killing Yazidi people. He was worried, quiet and had nightmares.

Illness onset

A classmate who had been granted permanent residency (PUT) in the spring 2016 said: "We are allowed to stay but all you from Syria have to go home". This triggered an acute crisis and he became quiet, stopped eating and moving. D became unresponsive on 13/05/2016. He was cared for in hospital, with nasogastric tube feeding, fluids and nutrition. Since that that time D is cared for in the home. No signs of improvement have been noted. He was not aware that a new asylum application had been submitted in August and rejected in December 2018. He has now been in a stuporous state for 3 years and 3 months. The parents have cared for him since May -16. The nasogastric tube is changed every 3rd month, and a dietician assesses him regularly. All hygiene is cared for in bed, with a change of nappy 3 times per day. He is turned in the bed every 30-45 minutes, also during the night.

Family

The father was depressed already in Syria and was treated there with sedatives. In Sweden, the father is seen by a medical doctor, and treated with anti-depressants and anxiety relief medication. The brother, 8 years of age, is worried in the night, wets his bed and is afraid of older children and animals. The younger brother, 11 months old, is the family's source of joy. The family has a contact person for respite care 3 hours/week. Child psychiatric input is ongoing.

Status

11- year old boy, not yet reached puberty. Laying with closed eyes. Normal height and weight. Has nappies. Ears: water behind both ear drums (causes hearing loss). Mouth and pharynx: bleeding gums. Weak swallowing reflex. Heart: Normal blood pressure and pulse. When a cold pack is placed on the abdomen the blood pressure remains unaffected (no reaction to cold stimuli). Lungs: Observations normal. Abdomen: Observations normal. Neurology/Psyche: pupillary response to light, eyes opened passively (normal). Tendon reflexes are normal. Babinski signs are normal. Leg muscles are weak. No signs of formal or emotional contact. Does not react to noise, touch, pain or cold. When the hand is lifted above the head, it falls onto the face without any startle response reflex.

Assessment: ***The condition is comatose-like and life threatening. Without a nasogastric tube the boy would be dead within 10 days. There is a high risk of aspiration of fluids and pneumonia when the tube is changed and during transport. Qualified multi-professional care and treatment is necessary. Treatment cannot be postponed.***

Case 2 E 12-year old Yazidi girl

Background The family come from a village in Northern Syria, where they have lived for three generations after fleeing from Turkey. E is number 2 of 3 siblings. She suffered a psychological trauma at the age of 3, when she saw her wounded mother be raped by "Arabs". The family fled to escape the granddad who wanted to kill the mother (honour killing).

An asylum application was submitted in 2011 and in 2012 the asylum application was rejected. A new application for asylum was submitted in August 2016.

Illness onset E was frightened when watching YouTube in 2014, when she saw what IS was doing to Yazidi women. After the school start in August 2017, her health deteriorated with daily headaches and feelings of dizziness. She became unconscious in school on 31/8 and was taken to hospital. A thorough examination suggested Resignation Syndrome. A nasogastric tube was inserted on 2/9. Since this time E has been cared for by her parents. After a second rejection on asylum application number 2 by the Swedish Migration Agency (MV) on 12/01/2018 and a rejection from the Migration Court (MO) notified on 02/06/2018, Resignation Syndrome was triggered in her younger sister too. Throughout this turbulent time E has not shown any reaction at all. She has been in a stuporous state, completely lethargic, with the exception that it has not been possible to open her mouth for nearly 2 years when she first fell ill.

Family The parents are powerless. They now have two ill children who both need fulltime, 24-hour, care. The help available in the form of support is from child psychiatry, the Red Cross and daily telephone contact with, and visits from, the girl's Swedish friends.
They fear the deportation to Syria where they are seen as idolaters (avgudadyrkare) and belong to a persecuted minority. They can never access the safety that is needed for the children to recover. They do not know whether or not there is health care available in Syria. As Yazidi people they have only been able to access jobs and help from a few employers. It is impossible to return to relatives since the threat of punishment from honour crimes remain due to the rape that the mother endured.

Status 12-year old girl who looks younger than her age. Eyes closed, has a nasogastric tube and nappies. Mouth: Impossible to open the bite. One of the front teeth is partially broken. Eyes: Averts. Pupils are not possible to assess. Heart: Observations normal. Lungs: Observations normal. Abdomen: Observations normal. Neurology/Psyche: Does not respond when spoken to or to touch, pain or cold stimuli (ice cube on the abdomen does not raise the blood pressure). Is laying completely still on the back without any formal or emotional contact. Body completely asthenic and lethargic. The head falls when she is lifted. She cannot stand on her legs. The arm falls limp over the face without aversion, when it is let go of above the head. Tendon reflexes are normal. Babinski normal.

Assessment
Comatose-like state, which is life-threatening. Without the nasogastric tube the girl will die within 10 days. There is a great risk for aspiration of fluids and pneumonia when the nasogastric tube is changed and during transport. It is not possible to suction the airways due to the fact that the jaws cannot be opened. Qualified multi-professional care and treatment is necessary.
Treatment cannot be postponed.

Case 7 Yazidi boy 15 years old

Background Brought up as number 2 out of 3 siblings in a Yazidi family in Syria. The parents have not been to school in their country of residence ['home country']. The father has been taught how to read and write a little when in Sweden. The mother was beaten and raped by three "Arabs" in 2009, when she was collecting water from the village well. The two oldest boys, then 6 and 7 years old, were playing outside. They saw their mother bloodstained and beaten to pieces. This frightened them and they cried desperately. The father was away from the home, working with digging the fields. The mother was pregnant and lost her child. The family escaped by foot through Turkey up to Istanbul. They arrived in Sweden by airplane.

Time in Sweden
In Sweden they applied for asylum but received rejection at all stages. Deportation has not been possible to carry out, as none of the countries (Armenia, Georgia, Russia, Iraq and Syria in war) accepts them. The children did not inform the parents about the rejection decision as they were sitting in the waiting room at the meeting about return. The mother sought psychiatric services and have been in contact with psychiatry over a number of years and is treated with anti-depressants and psychotherapy. The younger brother was born 2012. The father has had contact with a general practitioner and is on anti-depressant medication.

Illness onset.
Four years after the final decision, new application for asylum. New rejection on application by the Swedish Migration Agency (MV). Appeal to Migration Court (MD). When the decision from the Migration Court (MD) arrived in August 2017 the boy was home alone and read the decision. He became quiet, sad, angry, and had nightmares, started to withdraw and expressed suicidal thoughts "I shall kill myself". After a few weeks he stopped talking and stopped attending school. Did not have the strength to be with his friends, stopped eating and drinking. Nasogastric tube inserted and contact with child- and adolescent psychiatry where they resided. However, the family had to move a seventh time to a new place far away from where they had lived when the boy fell ill. The application for impediments to enforcement was rejected by the Swedish Migration Agency (MV) in March 2019.

Status. The body has now been laying unresponsive without swallowing reflexes, immobile, urinary and faecal incontinent for 1 year and 10 months. He has a high pulse of 120-160, indicating severe anxiety. In the long run this is a strain to his heart, and he risks early onset of heart disease (stroke, cardiac arrest, high blood pressure). He also has elevated liver values and a diagnosis of fatty liver disease. The liver blood counts are somewhat improved after the amount of food has been reduced but they are still not within normal range.

Assessment:
The condition is life threatening. Without a nasogastric tube the boy will die within 10 days. There is a high risk of aspiration of fluids/pneumonia when the nasogastric tube is changed and during transport. His exceptionally high pulse is a sign of anxiety, which increases his risks for early onset of heart disease. Qualified multi-professional care and treatment is necessary.
Treatment cannot be postponed.

Case 12 A 14-year old boy from Russia

Background Boy A was born in Russia as number 1 out of 4 siblings. The family moved from the city to the family's home village when he was 2 years old, as the father had to live in hiding because he was active in political opposition. On two occasions the father was taken by around 10 policemen, who broke through the door during the night, beat up the father and then took him away from the family. The father returned after around one month, after a large ransom had been paid, severely battered by the beatings.

The family escaped to Sweden in August 2008. A was terrified the first year when he saw uniformed guards. Speedy adjustment to Sweden, in nursery, school and after-school club. A has often had to interpret for his parents and has translated letters with asylum rejection decisions. He attended all meetings on return (7 in total) and reacted strongly to this. Last time, in May 2016, he laid down, stopped talking and within a week was found in a stuporous state. He could be fed through a syringe but due to weight loss a nasogastric tube was inserted in October 2016. Continued weight loss despite puberty with 15 cm gain in height.

Health status. 14-year old boy who has reached puberty, severely emaciated. Weight on the day 45 kg and 181 cm tall, which means about 20 kg underweight. Nasogastric tube through left nostril, has nappies. Is laying down, non-responsive, with eyes closed. Does not respond when spoken to, to touch, pain or cold stimuli (ice cubes put on abdomen), body completely asthenic and lethargic, the head is dangling when he is held sitting up. Cannot stand on his legs. The arm falls limp over the face without aversion when it is let go of above his head, tendon reflexes present but very weak, Babinski negative.

Assessment. F43.1 Posttraumatic Stress Syndrome (PTSD), F32.3a Resignation Syndrome. Resignation grade 2 according to the grading by the National Board of Health and Welfare (Socialstyrelsen). Grade 3 according to MAST Z 65.8. Is cared for by his parents in the home with nasogastric tube feeding, nappy changes and turns day and night, a care input that they are capable of, and which is equivalent to advanced health care. A is still after 3.5 years in a resigned condition, but with heavily stress-induced weight loss. It is unlikely that he will wake up from this durable condition under the present, unsafe, circumstances.

How can this condition be alleviated? *The health care input can only be expected to lead to an evident and durable improvement if the family is provided with safety. Although, there is still a risk for lasting physical and psychological damage*. Psychological contact will be needed for a long time in order to heal the psychological damage that this boy has suffered in his native country and after years of precarity in Sweden.

Assessment *The temporary leave to remain (TUT) 2x13 months that A and his family have been granted has not in any way contributed to the boy's condition improving. This family has now been 11 years in Sweden. Since A fell ill 3.5 years ago, his siblings have also been heavily affected.*
The family applied yet again for a permanent residency (PUT) in April 2019 but so far, they have still not received a decision from the Swedish Migration Agency. Yet another half year has passed. If another TUT is given to the family, A will remain in his stuporous state. He can barely be kept alive in Sweden with the current therapy/care support since the stress he is under means that he is unable to absorb nutrients. (Including 2 photos).

A still lives after 3.5 years in a devitalised state, but with heavily stress-induced weight loss. It is unlikely that he will wake up from this durable condition, under the present insecure circumstances. Only a permanent residency is life saving and curing!

Children and Youth with Functional Impairments

Children, adolescence and adults with disabilities are an exceptionally vulnerable group that clearly should be included in the application of humanitarian reasons.

Year 2014 the Minister of Justice at the time, Beatrice Ask, highlighted persons who are "suffering from serious illness or disability".

Needs for medical intervention in relation to disabilities:
Basic survival functions such as breathing, food and sleep are affected by brain injuries of various kinds and often demand advanced and coordinated medical interventions by medical doctors, nurses, speech therapist, occupational health, and physiotherapist. Acute interventions and operations involving shunt malfunctions in the brain, respiratory support against life threatening pneumonia and revoking of epileptic seizure demands speedy access to advanced health care and medicines in order to save lives.
The effect of many illnesses are damages to several organs and a combination of symptoms that many times can be specific to the individual. This means that the health care needs to be coordinated and requires solid experiences from various specialities. Some examples: patients who are fed through a nasogastric tube need particular and costly nutritional fluids. Patients with tracheostomy (breathing through a hole in the trachea) easily phlegm and must have suction acutely to prevent life threatening inflammation and infection in the lung tissue.
Self-harm leaves scar tissue and severe pain. When hips and other joints are misaligned that also induces severe pain. Physiotherapists' interventions are important to relieve this.
Speech therapists are important to speech and language training and dieticians for feeding or enteral nutrition.

Psychosocial input:
Except for medical interventions, psychosocial/pedagogic input in the form of communication using alternative means, can be developed based on the individual's abilities and enable the participation in society on equal terms- that is in accordance with their human rights.

Are there medical and psychosocial treatment resources in the refugees' countries of origin?
In crisis- and conflict-ridden countries health care resources are hard to come by and include a substantial shortage of medicines, hospital beds, health care materials, ambulances with small economic resources. This means that people with severe disabilities are rationed meaning interventions that are necessary for people with disabilities are not available in practice. In those cases where the patient belongs to a minority or a persecuted ethnic group the interventions are often non-existent. In many countries corruption and privatised health care means that health care in practice is not available to those who cannot pay for the high fees.

Cecilia Malmström, Licenced Psychologist

14-year old boy S from Central Asian country with an intellectual disability and autism.
(Summary of patient journal and medical certificates.)

Background. Boy S who came to Sweden in 2015 with his single mother M (the father died in the country of residence ['home country'], probably murdered). S has throughout his childhood in the country of residence ['home country'] been harassed, ridiculed and beaten due to his illness. Both the mother M and the son S have been through severely traumatising experiences and harbour a veritable fear of being forced to return.

Late, as often is the case in the asylum process when it comes to rape and sexual assaults, it was found out that M had been subject to rape by a man in a power position in the city. M was so traumatised and suicidal that she was admitted to adult psychiatry several times. The information about the rape was found out through the treatment and the psychiatrist addressed a specific medical certificate to the Swedish Migration Agency (MV).

After some time in Sweden, S showed signs of confusion, restlessness and loss of appetite, and was admitted to an acute psychiatric ward. After having been discharged he returned after some time, with signs of self-harm, aggressiveness and suicide risk. It was clear that he reacted strongly to insecurity, changes and stress. The mother is suffering from severe stress due to the risk of deportation.

Diagnosis for S: Q03.9 Congenital hydrocephalus, F41.2 Mixed anxiety and depressive disorder. F95.9 Tic disorder, unspecified, F 84.0 Childhood autism.

S has been admitted to the child psychiatric ward several times due to increased anxiety and depression and obsessive-compulsive disorder. The problems with his autism have amplified. S is prescribed neuroleptics and sleeping tablets.

S and his mother have had a large and warm support network in Sweden through a local volunteer refugee organisation where they have been living, and who have also been humanitarian spokespersons in contacts with the migration authorities and health care.

A dozen psychological- and medical certificates 2017-2019 and pleas from school and the Child and Adolescence Social Services have been submitted to the authorities:

Assessment: Brain injury due to hydrocephalus, severe disability, anxiety, depression, obsessive-compulsive disorder, behavioural problems and suicidal thoughts. There is a great need for continued intervention from a habilitation centre with occupational therapists, special education, physiotherapists, counsellors, psychologists and specialist medical doctors. These interventions will not be available to S in his country of residence ['home country']. A deportation to the country of residence ['home country'] is a very serious and threatening situation for this family. With a lack of adequate treatment, safety and predictability S risks developing serious additional psychiatric disabilities with chaos and premature death.

At the end of September 2019 at 04.00 in the morning, S and his mother are taken by the police, 5 persons, who takes them to the airport in Luleå and they are deported the same day with an extra chartered airplane to Kazakhstan. When they are dropped off, no reception has been arranged.

The mother then flees with her son to the nearest neighbouring country where they now live in hiding, without health care or medication for S or money for survival.

Case Presentations Functional Impairments

Case 10 F 14-year old boy from the Balkans

Early illness history At around 8 month of age, operated on for hydrocephalus with insertion of a shunt between the brain's third ventricle and the abdominal cavity through the throat, and a control was done after the operation. After that there were no further follow-ups. Follow-ups are a necessity as the shunt needs to be extended as the child grows. Six months after the operation the head starts to grow again, and the boy loses his ability to walk and stand, stops breastfeeding, and start to lose weight and his leg muscles start to atrophy. The parents contacted several medical doctors but were told that there was nothing they could do and that the "boy will die". At two years of age the parents contacted a neurosurgeon in the neighbouring country. The operation was recommended but could not be carried out due to high costs. The mother stayed at home to care for the boy. There is no access to school, exercise or physiotherapeutic treatment in the country.

Time in Sweden When the boy was 7 years of age the family came to Sweden. He started in a "training school" in the autumn of the same year and was given an assistant. In the school he had the opportunity to practice skills. In the beginning he was nearly completely unresponsive and was laying immobile on a mattress on the floor. After about a month he started to look around, lift his head, touch people's hands and smell. He started to listen to songs and babbles. He was operated on in order to have a new shunt fitted and some months later his hip-, knee- and ankle joints were operated on as these were stiff, slowly the boy started to walk on his knees and move himself using his arms. Despite the boy's multiple and complex illness condition and his young age, the Swedish Migration Board rejected the family's application for residency. When the boy was 9 years of age the parents divorced, and the father "disappeared" back to their country of residence ['home country']. The boy started to vomit, became quieter, worried and loud, and started to bite himself and hit his head.

Deportation One year later the rest of the family were deported under great commotion. After landing in the country of residence ['home country'], the Swedish police ordered an ambulance and then left the family at the airport. The ambulance refused to take the boy and left. None of the family members had any money, no passports and no telephone. After sitting on the pavement in despair, a taxi driver came and drove them to his parents, were they could stay. After about a week the boy became ill with a temperature, vomiting and hitting himself heavily on the head. The mother drove the boy to the hospital. At the hospital the mother ran towards the entrance with the boy but was stopped by the hospital staff who told them that they could not accept him as he was too ill. The staff went in and locked the doors. After three weeks without health care or help in the country of residence ['home country'], passports were arranged, and they travelled back to Sweden by bus.

Current situation. The boy's condition has deteriorated with increased worries and self-harm, screams and waking periods up to several hours every night. When he was 13 years of age, he was operated on his feet due to increased pain. After about a month the worries and screaming started again. The shunt catheter to the abdomen was underneath the skin and it turned out that it had become loose just below the valve, shunt revision was undertaken. At 14 years of age he had his first epileptic attack. A new operation is planned in the near future on his knees and hips to enable him to stretch his legs and start to practice standing. At 14 years of age he is mainly fed by his mother but can take the odd piece in his hand and put them towards his mouth. He babbles with multi-syllables, and possibly says mother. He puts on music on his play piano. He listens and looks enthusiastically at the fingers when the song "Incy wincy spider" is sung to him with movements.

Medical status Laying in bed, bed with gates plus height and lowerable head end, manoeuvres the bed on his own. He flicks in a photobook from school for long periods of time without looking at the pictures, at times he stops and looks intensely at a picture, holding it at about 10 cm distance. He has eye contact with his mother and his face lights up every time he sees her. The undersigned note no eye contact, cannot make him interested in things around him but he smells my hands and occasionally tries to bite. He waves his hands in excitement. Bites his wrists when he is upset. Has hit his left temple, red and swollen there. Cannot stand on his legs. Is in wheelchair. Holding up his head. Can turn from back to stomach and the other way around. Height 165 + cm. Head circumference 68 cm (enlarged). Weight 82 kg. Striae on abdomen and back (stretch marks). Indurations and bite wounds at various degrees of healing on both wrists. Scars after operation on ankle joints, knees, hips, groins and on the right side of the scalp, where a shunt can be felt. Contractures in knee-, hip- and elbow joints. Shows discomfort when attempts are made to stretch the joints. Misalignments in both feet. Right foot is limp.

Medical doctor's prognosis Severe disabilities with hydrocephalus and is dependent on the shunt working for the rest of his life. If the shunt stops working and he cannot access a speedy shunt revision his condition is life threatening. When the boy was deported back to the country of residence ['home country'] the last time, he was refused health care at the only hospital with a neuro-surgery clinic in the country. A return would in other words mean that he will die if the shunt revision is not carried out. The boy also has autism, cerebral palsy and profound mental retardation, which require a safe and calm environment as a prerequisite for him to be able to integrate the specific training, which is needed for positive development. The boy is attached to his mother, who is caring for him in Sweden, and who can help him with some training as she has been given continuous instruction from professionals in health and special education. There is no special education of that kind in the country where the family comes from, where home and school are collaborating to help persons with severe learning disabilities with autism. A placement in an institution, which is the norm there, would be a catastrophe for the boy; he would be separated from his mother, his most important emotional contact, and react with intense worry. This means that his self-harm would increase substantially, as would his habitual vomiting, which would offset his fluid- and salt balance, which in turn is life threatening. In Sweden, the conditions are such that the boy could develop and live a dignified life.

In 2012, the Swedish Migration Agency decided not to grant residency with reference to 5 Chapter 6 paragraph Aliens Act (2005:716).
In 2019, the Swedish Migration Agency decided not to grant residency with reference to 5 Chapter 6 paragraph Aliens Act (2005:716):

"It is not made clear from the present medical certificate that the {boy's} health status is so bad that it can be considered practically impossible to carry out the deportation. For that reason, there are no medical impediments to enforcements (…)
Serious illness can also be another particular reason of a kind, which could mean that enforcement appears as unreasonable. The present examination of impediments to enforcement is however not a re-examination of earlier invoked reasons and circumstances but in this examination the Swedish Migration Agency is only considering new circumstances (…).

[The boy's] health status- spastic diplegic cerebral pares, hydrocephalus with shunt, childhood autism and severe learning disability- have previously been subject to examination by the Swedish Migration Agency and the Migration Court. (…). The reasons cited with regards to shunt malfunction are assessed to be mere additions to already invoked and tried circumstances. According to the Agency the {family} has not evidenced with acceptable medical documentation that adequate health care is not available.
[The boy's] tonic–clonic seizures and contractures in the hip joint, knee joint, and elbow joint, are assessed to be the kind of deterioration of his general health that, in themselves, are new circumstances according to the Aliens Act. (…) Even taking into account an overall assessment of the new circumstances that have come to light in the case; {the boy's} health status is still not considered to have deteriorated to such an extent that there now would be reasons to conclude anything other than what the Agency and Migration Court previously concluded.
The Agency's view for that reason is that there are no new circumstances in {the family's} case, which would result in a deportation now appearing as unreasonable in the spirit of the Alien's Act. There are for that reason no medical impediments to the deportation (…)

A serious illness can also constitute another particular reason, which means that a deportation appears unreasonable. The existing examination of impediments to enforcement is however not a re-examination of previously cited reasons and circumstances; in this examination the Swedish Migration Agency only consider new circumstances (…)

[The boy's] health condition- spastic diplegic cerebral pares, hydrocephalus with shunt, infantile autism and profound mental retardation- has previously been subject to examination by the Swedish Migration Agency as well as the Migration Court (…) The reasons that are cited with regards to the shunt malfunction is assessed as merely an addition to what is already cited and tried circumstances. According to the Agency [the family] has not substantiated with acceptable medical documentation that adequate health care is not available.

[The boy's] tonic–clonic seizures and contractures in the hip joint, knee joint, and elbow joint, are assessed to be the kind of deterioration of his general health that, in themselves, are new circumstances according to the Aliens Act. (…) Even taking into account an overall assessment of the new circumstances that have come to light in the case; {the boy's} health status is still not considered to have deteriorated to such an extent that there now would be reasons to conclude anything other than what the Agency and Migration Court previously concluded.

The Agency is for that reason of the view that there are no new circumstances in {the family's} case that would result in a deportation now appearing unreasonable in the spirit of the Alien's Act. "

The boy and his mother were taken by the police and deported to their country of residence ['home country'] on the night of 20/11/2019.

Life Support Treatment

Regarding asylum seekers in need of life support treatment

Chronic kidney failure.
An individual who has been struck by severe chronic kidney failure needs regular dialysis treatment in order to survive; either haemodialysis 3 times per week or daily peritoneal dialysis. If the dialysis treatment ends the patient dies within a few days.

Right to health care that cannot be postponed
Asylum seekers have the right to acute health care and health care that cannot be postponed. When asylum seekers are diagnosed with severe chronic kidney failure, they have consequently the right to dialysis treatment in Sweden, since they otherwise would die. Several of these patients are later given rejections on their asylum applications, a decision that despite appeals are upheld. The law is referred to: A dialysis patient can be deported if dialysis exists in the asylum seeker's country of residence ['home country']. However, it is not taken into the consideration if the dialysis treatment is accessible to the person of concern.

What happens after deportation for people with chronic kidney failure?
An example that newspapers have reported on is the stateless Palestinian man Ahmed Amoura, who after nearly three years in Sweden, was deported. Amoura was taken by the police outside the dialysis clinic in Bollnäs and deported to Damascus in Syria. Since the police had not provided him with valid entry documents, he was detained immediately on arrival. The Swedish immigration police had not given Amoura permission to collect his medication from his house prior to deportation. Finally, after five days in custody Amoura, who at that stage was in a critical condition, was given dialysis at an official hospital in Damascus. The hospital did not have any resources to offer him dialysis treatment. If Amoura had not been helped with the payment for the treatment at a private dialysis clinic in Damascus, thanks to charitable fundraising in Sweden, he would have died. His survival is totally dependent on there being a flow of money from Sweden to support his dialysis. One can easily see what worry and fear that creates.

Another example is a man from Sudan who receives haemodialysis three times per week but who is threatened with deportation since there is information about a dialysis treatment in Sudan (state funded and free of charge for the patient). Testimonies from foreign physicians, however, bear witness to a shortage of dialysis beds.
There are also concerns that the shortage of dialysis beds has increased due to the conflict in Southern Sudan, which according to a country analysis by Lifos has led to an economic crisis with harsh living conditions for the Sudanese population. It is, hence, very uncertain if a dialysis patient who is deported to Sudan will receive dialysis treatment. However, without access to dialysis the patient is sentenced to death.

Is dialysis accessible for all in the country of residence ['home country']?
When it comes to deportation of dialysis patients it is not sufficient to note that there is dialysis in the country- we do not know how many dialysis-needing patients there are who are not receiving dialysis! One has to have guarantees that the patient will be receiving regular dialysis treatment. If these guarantees are absent the patient risks being without dialysis and dying within a week. It is incomprehensible that a country like Sweden, who claims to defend human rights, enforces deportations that can lead to death for asylum seekers.

Patients who have not had a dialysis bed secured in the country they are deported to, must be given residency on humanitarian grounds.

Astrid Seeberger, Consultant, Associate Professor, Specialist in Nephrology (Renal Medicine)

Case Presentations Dialysis and Leukaemia

Case M 49-year old man from Sudan
M suffers from chronic kidney failure and is completely without a functioning kidney function. He is completely dependent of regular haemodialysis 3 times per week for the rest of his life. If the dialysis is stopped, he will be dead within a week.

M has applied for asylum in Sweden but has been rejected and is now living under the threat of deportation to Sudan. According to a statement by the Medical Advisors Office, Immigration and Naturalization Service, in the Netherlands, from 29/11/2018 there is a possibility to access dialysis treatment at 2 different official dialysis clinics in the capital Khartoum. According the report, dialysis cannot be guaranteed to all patients.

In order for the patient not to die following a deportation to Sudan: from a medical perspective he must not travel to Sudan without a medical doctor from a dialysis clinic. This medical doctor will be the clinician who will be taking responsibility for the continued dialysis treatment in Sudan and he/she must also have been in contact with the patient's clinician at the dialysis clinic in Sweden to confirm continued treatment, the timing for the next dialysis and the handover process.

Certified in the service/on duty by the medical doctor and specialist in Nephrology (Renal Medicine) in charge

Boy K 6 years old from Kazakhstan
Patient journal information 15/04/2019- 01/10/2019
Originally from Kazakhstan. Risks deportation to the Czech Republic in accordance with the Dublin Regulation

In February 2019 K was diagnosed in South Korea with acute lymphoblastic leukaemia.
15/04/2015 K was urgently admitted to the child oncology ward at the Astrid Lindgren's Children's Hospital for continued leukaemia treatment. Assessed as Pre-B acute lymphoblastic leukaemia with intermediate risk C910, Z221 ESBL.
Is treated according to the Nordic protocol NOPHO-ALL 2008. K has after 6 months of treatment been evaluated according to the treatment protocol with bone marrow test with satisfactory results in terms of the treatment's effect on the tumour cells in the bone marrow. This means continued treatment according to the Nordic protocol for 2 years.
K has been cared for at the Child Oncology Ward due to difficulties in eating and has received nutrition through an in-situ, nasogastric tube. He has reduced strength in his legs. Due to low blood count levels he is at a high risk of infection. He remains in need of enteral nutrition, frequent hospital check-ups due to the low blood count levels. The plan is to start intense cytostatic treatment, 3-5 days per month, with polyclinic tests of blood count levels in between.

Assessment*: The health care input is life saving and essential. It will continue for 2 years and is expected to lead to an evident and lasting improvement. It is not medically justified to deport the patient to a Dublin country, as the risks with travel are great due to the high risk of infection during the ongoing cytostatic treatment.*

Fleeing from Afghanistan and Honour Culture

The escape from honour culture- Unaccompanied adolescents from Afghanistan

The text below is mainly gathered experiences from the Haninge Voluntary Family Homes (Haninge frivilliga familjehem), Hff, one of many associations around the country who assist families who have opened their homes for free for homeless unaccompanied adolescents: Youth who have lived in treatment homes for young people ("Hem för Vård eller Boende", HBV), which have been characterised by over-care, and who have been thrown out with around a weeks' notice as they have turned 18 years old or received a rejection on their application for asylum. We have/have had contact with around 50 youths of which around half have lived in family homes. We set clear expectations on good behaviour, school attendance, helping out at home, and not engaging in criminality or drug abuse. Of all the youth we have had contact with only 2 have had to leave their families due to drugs/criminality but we have still remained in contact and it seems now that they have understood the gravity of the situation. To set boundaries, is also love.

In our Association as well as the families there are also resource persons such as teachers and volunteers from, for example, the Swedish Church, the Red Cross and Save the Children. We have received support from local Rotary and Lions clubs, and local companies such as ICA food stores. In other words, we are an organisation with a broad reach in local contexts. Our experience is very good when it comes to people's wish to help when we are telling them the truth beyond fake news and the political parties' defamation of the youth.

Our work starts where the "legal guardianship" ends and the youths no longer have a right to their solicitors. Still they remain in the asylum process through their applications on impediments to enforcement. The "High School Law" (Gymnasielagen) is not part of asylum law; it is a "permit Act" (tillståndslag), which means that the youth do not have the right to solicitors when applying for residence permits or appeal decisions. Since the autumn 2015, we have gained substantial experience of the authorities' treatment of the youths, read numerous investigations and listened to stories, sat at bedsides when the anxiety and nightmares makes it difficult to sleep. We combine an increasing judicial knowledge with very close contact with the youth who in several cases have lived with us for about 3 years, i.e. over 1000 x 24 hours, per youth/family. There is an enormous amount we have to say but we shall focus on a number of areas that we feel are neglected in the debate:

Blood revenge
There are many stories about conflicts over land and actions of retaliation. Even when there is clear evidence that something has happened this is not taken into consideration. One boy has a long scar over his abdomen after his uncle tried to kill him after he had first killed the boy's father in order to access the relatives' land.

Another boy can very clearly describe how he as a child was guarding the sheep of a powerful man in the village, and how the powerful man's youngest son followed him into the mountains where Russian mines remains. Our little shepherd can describe exactly where the mines are left in the cliffs, but the powerful man's youngest son didn't know, and he died from stepping on a mine when our shepherd tried to make him go back home. For that reason, the father of our shepherd was killed, and the female relatives got the boy quickly on his way. He has been rejected on his application for residency on all instances.

Often the case worker states, "but you have been away for some years". However, the honour culture is resentful and does not magically disappear simply because somebody has lived in Sweden for a few years.

The Dance Boy System- Bacha Bazi

The Swedish Migration Agency undertakes many legal assessments but try and google to find relevant material that also contains instructions for case workers. We have only found material from other places but nothing about how the cases should be case worked. Here are some examples:

- A family disappears whilst an 8-year old boy is waiting in an hotel as they had some errands to do. The boy is sexually abused for 4 years as a "dance boy" until a person helps him escape. The boy has very strong and reoccurring crisis reactions. The case worker disregards his suffering with the words: "But you are 18 years of age now and what happened, happened a long time ago". In addition, they do not find that he is credible since he does not know what branded buildings there are in the town. Rejection. (After some time, he is granted residency according to the "High School Law" (Gymnasielagen)).
- After the parents had been murdered by the Taliban the older sister and husband sends the 13-year old boy to the Swedish Migration Agency and state that they did so in order for him not to be taken by the Taliban. The case worker claims never to have heard about the Taliban kidnapping boys.
- A 12-year old boy is kidnapped by criminals with connections to the Taliban movement and is raped, beaten and degraded in a basement by a group of adult men with hooded faces. When he is released after the family paid money, he could not walk, and he was incontinent and the whole Sunni Muslim- and hostile surrounding, understands what has happen. He is regarded as a despicable person, a scum, and he is at great risk of being killed so his family sends him away. It is very difficult for him to talk about this in Sweden and when he receives a rejection, he takes that as confirmation that Sweden also regards him as a dirty person. The rejection is based on the fact that vulnerability to abuse is not a reason for asylum. The Swedish Migration Agency and Migration Courts do not even categorise the abuse according to common Swedish law. Sexual crimes are regulated under another chapter in the penal code than violent abuse. Apparently, the migration authorities do not believe that boys suffer in the same way as women do from rape. It is not even categorised as serious criminal assault!

The youth do not often talk but when it happens it is not only about what has happened in the past but the fear of what would happen in the case of return. A boy who is turning 18 years old, who is small and "cute" says, "But you understand, I am not suitable as a soldier, I will be forced to become a dance boy". This boy is now in his 3rd year in a national program, economy and law and is amongst the best in his class- but he shall be deported!

Internal displacement does not exist.

How can anyone today with the Internet that reaches across the world believe that it is possible to live in hiding. In a country where it is dangerous to travel, the new communication systems can be even more important than in a well-organised country. Even in Afghanistan, the Internet is used when registering with authorities, getting a bank card, applying for work. We have noticed too that over the years that have passed since we first met the youth, more have managed to find a villager with Internet and so have been able to find out what has happened to their own families.

One unaccompanied minor has received a number of death threats from a man who was deported from Sweden to Kabul due to a group rape. Our boy helped the girl to report the rape to the police and could help in finding the perpetrators. The threats are of the kind: “I know that you are about to be deported and you are dead when you exit the airplane”. “You shall be chopped up like a dog”. The perpetrator is sending pictures of himself with a machine gun and also of him counting dollars. He belongs to a criminal gang in Kabul.
The Migration Court and the Migration Court of Appeal admit that the threats are real and as he helped the police. But they refer to the Swedish Migration Agency who claim that internal displacement is possible. At the same time these authorities are ignoring the Internet. The perpetrator has over 2000 friends on Facebook and they are dispersed across Afghanistan. Our unaccompanied minor is the same boy who has the scar on his abdomen after the murder attempt by his uncle. He has, in other words, no network who can protect him.

The burden of proof

The burden of proof is so strict that the death that people escape from has to occur before they are believed. One boy belongs to the Afghanistan national team in a sport that IS and the Taliban, consider western and decadent. First the trainer was murdered, then a team-mate, and then another team-mate. Rejection in 2 instances with the justification that there is no evidence that he is next in line. The murders have received great media attention on Afghanistan TV and the boy can show screen shots. However, unfortunately the Taliban do not give warnings beforehand so the only way to prove this is that the boy is dead.

By the letter interpretation.

The application regarding residency can according to the “High School Law” (Gymnasielagen) be rejected since the boy has already applied and been rejected. However, Social Services in Stockholm did not manage to find his notes in time and have apologised for this and admitted that they are at fault. But this does not matter.

Conclusion

The examples are as many as there are persons. Not everyone has clear refugee reasons, unless one declares Afghanistan as a country in civil war, which it could very well be categorised as.

However, it is surprising that a country like Sweden who so clearly declares that one shall combat the honour culture, do not see that as a possible reason for asylum- the honour culture’s worst manifestations fit very well within Sweden’s International Convention commitments- both for men and for women.

The most negative application of the law has only one aim and that is that as few as possible should stay in Sweden. As such it means nothing if there is an application of the law, which is completely new to Sweden.

Haninge 09/11/2019

Carin Flemström
Chair
Haninge Voluntary Family Homes (Haninge frivilliga familjehem)

Case Presentation Boy with Cultural Attachment

Case 11 Dani 13 years of age from Kyrgyzstan
Dani's family were persecuted in their country of residence ['home country'] due to ethnic discrimination but also by criminal networks. The mother is Russian, and the father is Uighur, the children have the father's, so called, nationality in their domestic passports. Dani's father had been a witness in a trial in 2010 against the people responsible for the June unrest, which led to 25 warmongers and murderers being imprisoned. These people are part of a criminal network, involved e.g. in international drug smuggling. After several less serious incidences at home in the village the family's car was forced off the road in 2011 by a car with items of police uniforms placed visibly; they were assaulted and threatened with much worse if Dani's father did not change his witness statement. Dani was thrown against a tree and was concussed and has several typical posttraumatic stress (PTSD) symptoms and is afraid of other children. Due to the ongoing persecution they had to live in hiding for ½ year until they escaped to Sweden. Several of the criminals were able to bribe themselves out of prison and since January this year, the Kyrgyzstan president has issued a general amnesty for all prisoners. The previous president, who took responsibility for the trial in 2011, has recently been imprisoned.

Since 2012 the family has lived in Sweden. They have been able to work and support themselves financially in periods. After the rejection on their application for asylum in 2014 they have been living in hiding with the help of friends in terms of housing and food. Dani and his brother have liked being in their nursery and school. The parents, who are used to being discriminated against at all levels of society, feel that it is wonderful that their children can attend a school that treats all children as equal. Dani is talented and motivated and achieves high grades and is a "maths genius" according to his teachers. He and a friend have started a "Don't Touch My Friend" ("Rör Inte Min Kompis") group for children who are bullied.

In 2017, the family applied for asylum again with the support of an investigation carried out by the US Department of State (the Swedish Migration Agency's document title (in Swedish): "Hur är möjligheten till myndighetsskydd för personer som hotas av kriminella gäng eller personer" [in English: What are the possibilities for State protection for persons who are threatened by criminal gangs or persons"], Lifos 2016 doc 38283, 161007650 pdf). The document states that societal protection for the civilian population is missing in Kyrgyzstan. Extremely low salaries mean that police and lawyers are living on bribes from criminals and cannot intervene. The Swedish Migration Agency stated in the asylum decisions: 1/The family should turn to the police if they are harassed in their country of residence ['home country'], 2/For children below 15 years of age, family unity is the only thing that is important.

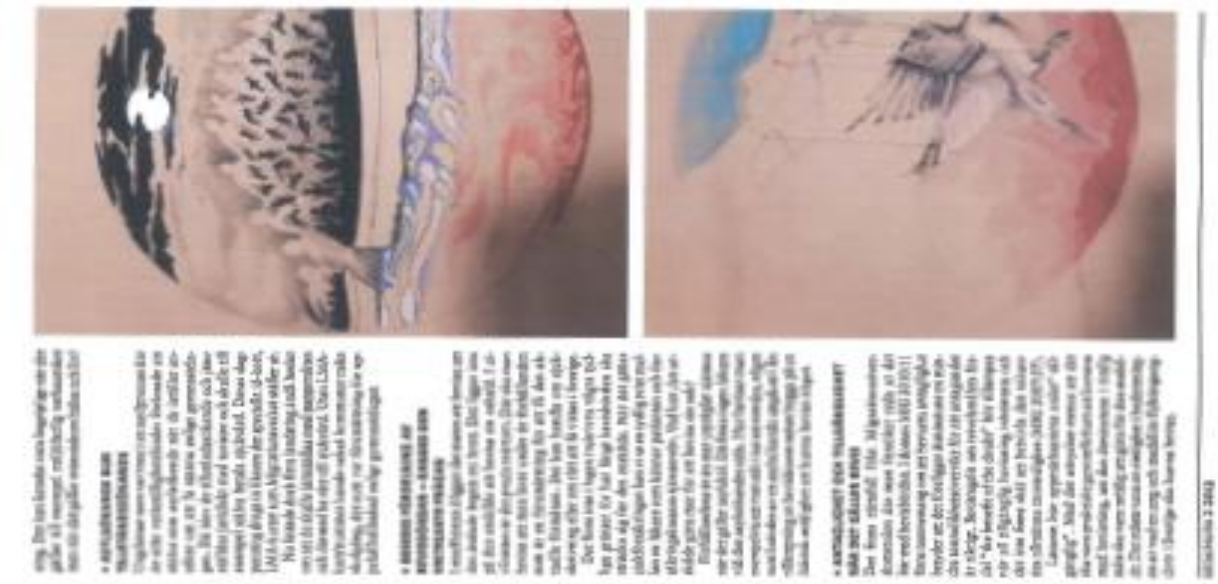
In the case of a deportation, Dani's father would when he exits the airplane be identified by the named criminal network and be killed soon after. The network is present across the country and within all authorities. To turn to the police without bribes leads to criminal groups instead being handed over the case, according to the detailed study by the Internet magazine "Belyj Parus" (White Sails) 2017. The only possibility would be to hide at Dani's grandmother's, who is a widow and a poor pensioner, living in a 1-room apartment. If Dani's father is imprisoned or murdered, Dani's mother will have to provide for the family. She belongs to the previous Russian ethnic- and language group, that used to hold power, and does not speak the national language. For that reason, she is, despite a high educational level, in effect discriminated against in the labour market.

Dani and his brother, who do not speak the new majority language, would in their country of residence ['home country'] be forced to start the first year in school, if they at all would be permitted to attend school at all, which is regulated by strict ethnic laws: all citizens must have a domestic passport where the nationality (ethnic belonging) is an obligatory piece of information. The ruling majority group is systematically repressing other groups. The school is for the ethnic group that has the power in the country. The school is for that reason a single language school, children are only educated in Kirgizia and are forbidden to speak in minority languages. This practice has from August this year been officially announced by the Prime Minister at a conference for the national education system (reference in Belyj Parus 23/8 2019). Only 50% of the children in the country attend school. Children from minority groups are asked to pay a higher fee for schooling. Only children with parents who can prove that they own their accommodation have the right to attend school. The children have to be put on a waiting list and the parents have then to pay visits to civil servants several times per year with bribes in dollars (edu.gov.kg/ru/school/school-docs) in order to remain on the waiting list. According to Transparency International the country is riddled with corruption- the whole school- and educational system, as well as the courts and the police.

School means paying for fees and costs for school uniform, books, food. Added to that are "volunteer fees" for teachers' salaries and the heating of the school and maintenance. Again, it is the low salary of the teachers and corruption at all stages that means that the money from the county councils/municipalities disappears on the way, reference 24.kg/obchestbo/obrazovanie_inauki_kyrgizistana). A list ranks the children according to their families' economic contributions to the school. Pupils on the lower part of the list are treated negatively by the teachers, receive lower grades and are harassed by pupils higher up on the list. The teachers and the principal must also be bribed in order for the children to get the grades, which could move them up to the next class. After primary and secondary school every step to continued education is in practice reliant on belonging to the present national (ethnic) majority and on fees and demands for bribes. Since 2019, in order to be eligible for higher education, a pass in Kyrgyz is needed (Belyj parus 38/8 2019).

Extracts from Publications

Article in Swedish, reference: Flemström, C. Rättsosäkra Migrationsbeslut [in English: Legally uncertain migration deliberations]. Socialpolitik 2019 no. 2, at: https://socialpolitik.com/2019/11/06/rattsosakra-migrationsbeslut/.



Rättosäkra migrationsbeslut

Individer i underläge genomsyr myndigheter

• GÅR DET ATT UPPFYLLA KRAVEN FÖR TROVÄRDIGHET?

• ETT JURIDISKT BITRÄDE SOM INTE HAR RÄTT ATT TA FRAM BEVISNING

• DÖDSHOT – ÄRENDE AV ENKEL BESKAFFENHET

• INTERNFLYKT – FINNS DET?

"Om politiker står upp för humanism får de folk med sig. Människor litar på den som vågar stå upp för sina åsikter."

• MÄN KAN INTE VÅLDTAS

• KONVERTITERS OCH HOMOSEXUELLAS SITUATION

POLITIKER OCH DOMSTOLAR BLUNDAR

MIGRATIONSVERKET FÅR SLÅ SKOTT

TEXT: CARIN FLEMSTRÖM
ORDFÖRANDE FÖR HANINGE FRIVILLIGA FAMILJEHEM SAMT FÖR BROTTSOFFERJOUREN I HANINGE NYNÄSHAMN

BILD: MAHAS MAJAD, ENSAMKOMMANDE FRÅN AFGHANISTAN OCH KONSTNÄR

FAKTA:

LÄS MER:

Article in Swedish, reference: von Knorring, A-L, Sjunghamn, A, Gyllenring, K. (2019). Svårt sjuka barn sviks [in English: Severely ill children are being let down]. Upsala Nya Tidning 18 November, at: https://www.unt.se/asikt/debatt/svart-sjuka-barn-sviks-5138497.aspx.

Svårt sjuka barn sviks

Myndigheter sviker lagstiftaren och barnen, då barn med uppgivenhetssyndrom inte får permanent uppehållstillstånd, skriver en barnpsykiater och två advokater.

Professor emerita Anne-Lis von Knorring och advokaterna Anuta Sjunghamn och Karin Gyllenring menar att Begränsningslagen används felaktigt.

Apatiska barn

När lagstiftaren år 2006 beg ansade människors möjlighet till uppehållstillstånd i Sverige och gjorde tillfälliga uppehållstillstånd till norm i stället för permanenta uppehållstillstånd gjordes ett undantag för riktigt sjuka barn.

Om det bedöms att det finns synnerliga ömmande omständigheter relaterat till varaktigt nedsatt hälsotillstånd så skulle barn kunna få permanenta uppehållstillstånd i stället för tillfälliga.

Syftet var att de riktigt sjuka barnen skulle få leva i trygghet då deras hälsotillstånd absolut krävde det.

Vi som arbetar med barn som lider av uppgivenhetssyndrom, de så kallade apatiska barnen, utgick därför från att barnen i de fall där ett tillfälligt uppehållstillstånd skulle omöjliggöra effektiv vård istället skulle beviljas permanent uppehållstillstånd. Barnen skulle ges en årlig chans till ett tillfrisknande. Det var trots allt lagstiftarens syfte, men så har det inte blivit i praktiken.

Barn som lider av uppgivenhetssyndrom får i stället i bästa fall enbart tillfälliga uppehållstillstånd, trots utlåtanden från barnläkare och specialister vilka bedöms att barnets hälsotillstånd absolut kräver ett permanent uppehållstillstånd.

Myndigheterna motiverar det korta tillståndet med att uppgivenhetssyndrom inte utryckligen nämns i förarbetena till bestämmelsen.

Under drygt 15 år har många asylsökande flyktingbarn insjuknat i detta tillstånd, vilket initialt kallades "apatiska" barn och sedan 2004 finns uppgivenhetssyndrom som officiell diagnos. Därför vet man i dag att det under 2016 vårdades knappt hundra barn under 18 år med uppgivenhetssyndrom i Sverige. Sannolikt har antalet barn med denna diagnos varit relativt stabil under senare år.

Uppgivenhetssyndrom är ett psykiskt tillstånd som är livshotande.

Hos barn förekommer tillståndet främst hos dem som utsatts för svåra traumatiska händelser. Barnen med den svåraste formen av uppgivenhetssyndrom är helt okontaktbara.

De vägrar inte mat och dryck, när sig inte alls och reagerar inte even på smärta. Barnen behöver ständig hjälp med total omvårdnad och i de flesta fall måste man sätta en sond ner till magsäcken för att tillföra livsnödvändig vätska och näring. Behandling med sond kan dock ibland leda till komplikationer som kan vara livshotande. Exempel på detta är att risken för att andas in magsaftshåll ökar till exempel vid transporter med flyg. Då kan en kemisk lunginflammation uppstå, som inte går att bota med antibiotika.

Dessutom måste skador på grund av att barnen är orörliga förebyggas. Enderna får inte stelna och musklerna behöver passiv träning. Dessa åtgärder leder inte till att barnens tillstånd förbättras, utan är endast livsuppehållande och för att ingen ytterligare försämring ska ske.

Alla dessa barn har utsatts för återkommande våld eller övergrepp, antingen själva eller bevittnat hos nära familjemedlemmar.

Diagnosen har de flesta barn och

> **Uppgivenhetssyndrom är ett psykiskt tillstånd som är livshotande.**

deras familjer varit utsatta för förföljelse i hemlandet på grund av etnicitet, religion eller politisk aktivitet. När de förlorar trygghet i hemlandet, eller väljer att de inte får vistas i det tryggare land de sökt sig till, lär sig dessa barn inte av att bemästra den stress och skräck de utsatts för. Symptomen blir då så svår att de går in i det uppgivenhetssyndrom. Tillståndet kan lossna i många år om inte hopp, säkerhet och trygghet kan återkommas. Även om barnet är oåterkalleligt kan det känna av stress eller lugn i sin omgivning.

Dessa barn behöver psykiatrisk vård och behandling, men för att kunna tillgodogöra sig detta behöver de vara mottagliga och närvarande, och världen behöver tillhandahållas i en för barnen trygg och säker miljö.

Barnen behöver således återfå hopp, trygghet och känna sig säkra tillsammans med sin familj för att kunna förbättras. Vi vet detta av erfarenhet. Barnläkarna vet detta. Myndigheterna vet detta. Och lagstiftaren vet detta.

Här §58 i Begränsningslagen införlivades nämnden inte tillståndet uppgivenhetssyndrom utryckligen i förarbetena, men det får anses vara klarlagt att uppehållsrätt av sådana synnerliga tillstånd, där ett tillfälligt uppehållstillstånd kan komma att omöjliggöra effektiv vård inte är tillämpande, utan en exemplifiering. Mot bakgrund av att svenska rättsregler ska tolkas förenligt med internationella konventioner, utgör tillståndet uppgivenhetssyndrom ett sådant allvarligt hälsotillstånd där permanent uppehållstillstånd kan (ska) beviljas.

Så varför finns det fortfarande barn i Sverige som lider av uppgivenhetssyndrom och vars allvarliga och livshotande sjukdomstillstånd absolut kräver ett permanent uppehållstillstånd, men som istället bara beviljas ett tillfälligt uppehållstillstånd eller än värre får ett utvisningsbeslut?

Vårt Sverige ska ta hand om barn. Lagstiftarens syfte var att barn skulle tas om hand. Ändå sviker de tillämpande myndigheterna oss, de sviker lagstiftaren och de sviker barnen – de allra viktigaste.

Paragraf 18 i Begränsningslagen finns för att bevilja barn med uppgivenhetssyndrom, och vars allvarliga och livshotande sjukdomstillstånd absolut kräver det, ett permanent uppehållstillstånd. Det är därför dags att myndigheter börjar tillämpa bestämmelsen korrekt och i enlighet med lagstiftarens syfte. Något annat är ohållbart i vårt rättssamhälle. Något annat är oacceptabelt i ett land där vi ska värna om barnets bästa.

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Article in Swedish, reference: Lönnerblad, V., Heilborn, C. 2019. Svårt sjuka barn ska inte utvisas [in English: Severely ill children should not be deported]. Svenska Dagbladet 19 May, at: https://www.svd.se/svart-sjuka-barn-ska-inte-utvisas.

”Svårt sjuka barn ska inte utvisas”

De allra mest utsatta barnen drabbas hårdast av den tillfälliga utlänningslagen. Lagen som infördes 2015 förlängs nu i väntan på att en permanent migrationslag ska tas fram. Vi vill varna för att den nya lagen kan innebära fortsatt kraftiga försämringar för de barn som är i mest behov av skydd, skriver Véronique Lönnerblad och Christina Heilborn, Unicef Sverige.

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”Svårt sjuka barn ska inte utvisas”

Véronique Lönnerblad och Christina Heilborn. Foto: Pressbilder

DEBATT | ASYLLAGEN

Länge fanns de humanitära skälen som ett komplement i svensk lag för att skydda de mest utsatta bland de asylsökande. Barn har kunnat beviljas uppehållstillstånd på grund av så kallade särskilt ömmande omständigheter. Det innebär att till exempel svårt sjuka barn, eller barn som har omhändertagits på grund av våld i hemmet, har fått möjlighet till uppehållstillstånd. Särskilt ömmande omständigheter har också omfattat barn som saknar familj, eller barn som länge vistats i Sverige och saknar nätverk i sitt ursprungsland.

När den tillfälliga utlänningslagen infördes 2015 innebar det inte bara att permanenta uppehållstillstånd ersattes av tillfälliga, och att familjeåterföreningen kraftigt begränsades. Möjligheten att få uppehållstillstånd på grund av humanitära skäl stramades också åt. Sedan dess har regeringen föreslagit att rätten till familjeåterförening ska utökas, vilket är positivt. Ingen lättnad har dock aviserats när det gäller restriktionerna för de humanitära skälen.

Regeringen ska nu tillsammans med stödpartierna besluta om hur den permanenta migrationspolitiken, som ska gälla efter 2021, ska se ut. En ny humanitär skyddsgrund ska tas fram, men hur den ska utformas är inte klart. Vi har med oro sett hur de humanitära skälen har begränsats, och vi är fortsatt mycket oroade över att barns särskilda behov av skydd inte kommer att säkerställas i den nya permanenta migrationslagstiftningen.

Regeringen har valt att göra barnkonventionen till svensk lag, och Unicef Sverige anser inte att det är möjligt att samtidigt fortsätta att driva en migrationspolitik som inte ger de mest utsatta barnen skydd. Stramar man åt de humanitära skälen för barn innebär det att det yttersta skyddsnätet försvinner för de mest behövande. Det kan till exempel handla om ett barn med en svår hjärtsjukdom som har opererats i Sverige, men som sedan utvisas till hemlandet trots att nödvändig behandling och efterföljande vård inte är tillgänglig där.

Vi ser tydligt att det har utvecklats en allt hårdare praxis i Migrationsverkets bedömningar och i domstolarna. Statistik från Migrationsverket från åren 2013–2015 visar att av de barn som beviljades uppehållstillstånd fick cirka 10 procent det på grund av särskilt ömmande omständigheter. År 2018 var motsvarande siffra 3,4 procent och hittills i år rör det sig om cirka 1 procent.

Unicef Sveriges oro delas inte bara av en rad organisationer inom civilsamhället utan även av Migrationsverket. Myndigheten har uttalat att det med nuvarande lagstiftning kommer att fortsätta behöva utvisa svårt sjuka barn som tidigare beviljades tillstånd. Migrationsverket anser att bestämmelsen om särskilt ömmande omständigheter bör återinföras. Verket ser svårigheter med att tillämpa nuvarande lag och vill ha klargöranden om hur den stämmer överens med barnkonventionen som blir svensk lag nästa år. Unicef Sverige delar helt den uppfattningen. Vi ser även att det finns starka skäl att ifrågasätta huruvida den permanenta lagen kommer att beakta barnkonventionens bestämmelser i tillräckligt stor utsträckning.

Om Sverige vill vara ett land som lever upp till att främja en human flyktingpolitik måste de mest utsatta barnen skyddas. Vi anser därför att särskilt ömmande omständigheter för barn ska återinföras som en humanitär skyddsgrund och bli en del av den framtida migrationslagstiftningen. Allt annat vore ett svek mot de mest utsatta barnen.

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