

CASE PROGRAM 2013 -151.1

Sweden's apathetic refugee children (A)

In early 2005 Swedish media highlighted the strange case of some 150 children who had suddenly fallen into a state of apathy. The children had stopped talking, eating or drinking and connecting with the world around them. They were unwilling or unable to move, spending their days in a vegetative state. Several were admitted into psychiatric care and had to be tube-fed. The children's medical condition was unprecedented and did not fit any of the diagnoses in the standard Diagnostic and Statistical Manual of Mental Disorders (DSM) or the International Classification of Diseases (ICD-10). Even though they came from war-torn countries, none of the children had been living in war zones or exposed to traumatic events of war.

The affected children all came from families (mostly from the former Soviet Union and Yugoslavia) who had filed for political asylum in Sweden. Some families already knew that their applications had been rejected, and were appealing against scheduled deportation. Others had arrived from countries considered to be safe by the immigration authorities, so it was likely that their applications would be rejected. Swedish immigration policy had strictly followed the Geneva and Dublin conventions and only granted asylum for "humanitarian reasons" in the absolute minimum of cases. However, under the UN Child Protection Act children with a serious health condition, and therefore their parents and siblings, could not be deported.

Politicians, researchers and doctors were all bemused at this new phenomenon. The issue divided Swedish public opinion at a time when a right-wing populist party was growing in electoral strength, seriously threatening the incumbent Social Democratic government.

The government's immediate response was to try to speed up the asylum decision process for "at risk" families, commissioning a report by child psychologist Dr Marie Hessler. Appointed National Coordinator, Dr Hessler was asked to analyse the scope of the problem, to work with

This case was written from published materials by Associate Professor Karl Lofgren, Victoria University of Wellington, with editorial assistance from Janet Tyson, Australia and New Zealand School of Government. It has been prepared as a basis for class discussion rather than to illustrate either effective or ineffective handling of a managerial situation.

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the local health providers and if possible to prevent the problem from becoming epidemic. "It is tremendously important that we are able to identify the children and families at risk at an early stage, so they can receive appropriate help and support," said the Minister for Migration Ms Barbro Holmberg, when she initiated the report in the autumn 2005. "Their cases must be given top priority to keep the time they have to wait for a decision as short as possible."

The experts working in Dr Hessler's team included a sociologist but no psychiatrist. Rather than trying to make a new "diagnosis", their approach was to investigate a new "behaviour", without taking into consideration any possible medical causes. The team sourced the available evidence, including searching medical and organisational databases, sent fact-finding missions to the countries of origin of the refugee families, and interviewed a number of medical specialists from national health providers, as well as UN organisations and NGOs such as the Red Cross and Médécins sans Frontières. They discovered that the apathetic state was unknown elsewhere, and could only be identified in the cohort of refugee children in Sweden.

Consequently, the final report penned by Dr Hessler indicated that the children may have been faking the condition. As well, sections of the media were suggesting that some of the children were malingering, or had been drugged and poisoned by their parents. Some regional health providers then attempted to take blood samples. However, a number of families refused to let blood be taken from their children for cultural reasons, and most Swedish laboratories rejected to analyse them for ethical reasons. Those samples which the authorities managed to take were sent for analysis in the UK. None of the test results indicated the use of drugs, and all sides eventually agreed that the accusations could not be proved.

Several charities working with refugees also disputed the findings of the Hessler report and the government approach. Doctors and researchers began to come forward with suggestions that the phenomenon was known to occur elsewhere, and that the government coordinator and her team lacked the necessary psychiatric competence. A group of doctors formed the 'Union of Physicians for Refugee Children', pushing for a medical diagnosis and for hospitalisation not only for the children but for their whole family. Religious and voluntary organisations in several Swedish towns organised demonstrations in support of the children, showing no doubt whatsoever that they were suffering from a genuine and serious condition.

However, with even one of the main advocates for the apathetic children, paediatrician Dr G Bodegaard¹, acknowledging that at this point there was a lack of diagnostic medical criteria, a highly politicised situation was created. A number of parties in parliament (representing both the opposition and government supporters) pushed for an amnesty for the children. In the meantime, some of the families were granted residency on basis of their children's conditions.

Exercise

Based on this brief information, how would you as policy adviser:

- a) Identify evidence for policy-makers? Which sources would you use?
- b) Handle a case so politically sensitive?

¹ Bodegaard, G. (2005) Pervasive loss of function in asylum-seeking children in Sweden, *Acta Paediatrica*, 94:1706-1707