

A NOTE ON ROMA MENTAL HEALTH AND THE STATEMENT BY GÉZA JESZENSZKY

ANDREW RYDER-BEÁTA NAGY-IULIUS ROSTÁS¹

ABSTRACT The following note provides an overview of the debate centred on a 2005 course textbook which was written by Géza Jeszenszky for courses he taught at the Corvinus University of Budapest. In the text book a claim was made that many Roma are mentally ill on account of Roma culture sanctioning incestuous relations. The note refutes this claim and can find no scientific evidence to support such assertions.

KEYWORDS: Roma, Consanguinity, Negative Framing, Disability, Poverty

In 2005 a course textbook was published which was written by **Géza Jeszenszky**² and used for courses taught by Jeszenszky at the Corvinus University of Budapest. In the text book there is a sentence which generated a great deal of debate and criticism:

The reason why many Roma are mentally ill is because in Roma culture it is permitted for sisters and brothers or cousins to marry each other or just to have sexual intercourse with each other. (Jeszenszky, 2005, 273)

1 Dr Andrew Ryder is a Fellow at the University of Bristol and Visiting Professor at the Corvinus University of Budapest (CUB), Dr Beáta Nagy is an Associate Professor at CUB and Iulius Rostas is a Visiting Lecturer at CUB. The authors wish to express thanks to Dr Agnes Havril (CUB) for translating some texts and to Oláh Tamás of CUB for some research and cataloging support. In addition, the authors wish to thank Dr Sarah Cemlyn of the University of Bristol for reading a draft of the paper and providing invaluable comments. E-mail: andrew.ryder@uni-corvinus.hu

2 The course book has not been used for two years as Jeszenszky took up the post of Hungarian ambassador to Norway in 2011

Critics argued that the sentence gave credence to racist perceptions which imply that Roma commit the crime of incest (which is prohibited by law) as part of their culture, hence connecting crime to culture and contributing to racial profiling. In addition, the statement was also considered pejorative towards people with disabilities, implying that some of them may be the result of incestuous relationships. Jeszenszky is reported to have told the television channel ATV in October 2012 that the chapter in question was supported by academic research (Politics.HU, 2012). However, in November 2012 at the Roma Club Foundation Jeszenszky reportedly denied charges of racism and stated that he would formulate the sentence differently if he were to write the text today (Budapest Times, 2012a).

In November 2012 the Rector of the Corvinus issued a statement which declared that the Corvinus University did not agree with the sentence (Budapest Times, 2012b). Péter Csermely (newspaper columnist), in a *Magyar Nemzet* (newspaper) editorial, responded to criticism of Jeszenszky's sentence and stated that the author had simply drawn some conclusions from "evident facts", "supported by many researchers" (*Magyar Nemzet*, 2012). It was suggested in late 2012 that the Corvinus University establish a commission to provide an academic and scientific statement on the sentence with a view to seeking Jeszenszky's endorsement of this note and clarifying the actual opinions of experts on these matters. It is hoped that the note will diminish the damage caused by confusion and or acceptance of unsubstantiated claims. In May 2013 at a conference on Roma issues hosted by the Corvinus University the Vice Rector Zoltán Szántó stated that he now felt it was an appropriate time to initiate the commission. The commission consists of a number of academics who are the authors of this note. It is the view of the commission that the claims in the aforementioned paragraph cannot be sustained. In the scholarly literature there are no references to Romani culture sanctioning incestuous marriages and relations. Negative framing has throughout the centuries featured in the depiction of this minority as 'folk devils' and 'dangerous outsiders' who are sexually licentious and do not conform to societal norms (Nirenberg, 2011).

A review of health literature on Roma communities conducted by Hajioff and McKee (2000) notes that in a Spanish study of congenital malformations in the Gypsy population (Martínez-Frias and Bermejo, 1992) it was found that recessive syndromes were seven times more common than in the reference population, a finding attributed to consanguinity (which was 12 times as common as the majority population). The literature review argues that high rates of consanguinity have been reported among Roma populations elsewhere. However, such consanguinity appears amongst cousins, not

brothers and sisters³. To verify this fact the commission contacted Professor McKee CBE (European Centre on Health of Societies in Transition at the London School of Hygiene and Tropical Medicine), whose literature review is cited above. He informed us that:

I am aware of no evidence that supports the assertion made by Dr Jeszenszky. As you note, consanguinity exists in many communities worldwide but any contribution that it might make to the health of the Roma population must be quite minute, if it exists at all. The clear finding of our research was that the overwhelming explanations for the poor health of the Roma lay in the adverse social and material environments in which they lived, in large part reflecting the long standing discrimination they have faced over centuries.

In a letter sent on the 1st October to Péter Molnár and co-signatories Professor Ian Hancock and Frank Mugisha, who had written to Jeszenszky's expressing concern about his claim, Jeszenszky states that he drew his assertion from a 1994 Romology textbook '*Tanulmányok a romológia köréből*' (selected papers from the Foundations of the Romology Course) from Pécs University, where a student/teacher (Jakab Istvánné) described the situation of 24 disadvantaged Roma families in a small village and claimed, among other things, that a large number of the elementary school pupils whose parents are likely to be related are either physically or mentally impaired (Jeszenszky 1st October, 2012). However, a detailed analysis of the methodology and research approach of this study raises some serious concerns. As for the research methodology, on page 40 the author states that she "examined" the children's groups at the school, personally asking children the questions in the questionnaire during informal conversations in the breaks between classes where she was surrounded by a group of other children, with occasional personal interviews. She visited 24 families. The author did not circulate the questionnaire in advance, as she stated it was well

3 The term 'consanguineous' is from the Latin consanguineus, meaning 'of the same blood'. Consanguineous unions involving first cousin marriage is permissible under civil law in virtually all countries. According to Saggar and Bittles (2008), the lowest rates of consanguinity are found in Western Europe, North America and Oceania, where less than 1% of marriages are consanguineous (i.e. unions between couples related as second cousins or closer). In some parts of Southern Europe, South America and Japan, 1–5% of marriages are consanguineous. The highest rates of consanguineous marriage have been noted in North Africa, the Middle East and much of Central and South Asia, where more than 25% of the world's population lives, and unions between couples related as second cousins or closer can account for $\geq 50\%$ of all marriages.

known that many of them were illiterate, and she declared that some questions had to be explained to interviewees.

Regarding the questionnaires (detailed on page 61 of the textbook), the author describes her “somatic and psychological examination of the students”, which included questions on: weight at birth, weight and height in the 1st year of school, whether the student had any hearing or visual impairment or was undernourished. A final question refers to psychological status and lists options like crying during the day or night, incontinence, and so on. The author does not make clear how she got the answers to these questions, but we may assume that she simply asked either the family members or the children themselves. The author makes no reference to the use of official medical records or other documents. One question refers to the number of family members with the following characteristics: mental or physical disabilities, being illiterate, an alcoholic, or having a criminal record. The author makes no reference to having asked questions about who is married to whom and no reference is made to sexual relations in the questionnaire. Yet, on page 42, the first sentence states that “blood relationships occur in 15 out of 24 families” and goes on to say that there have been marriages between cousins, half sisters and brothers and “other variations”, with one case where the spouses were half siblings with the same mother. Another Gypsy is said to have married his sibling’s daughter. There are several cases where the author says that the situation was the same in the older generation too. It is important to note though that the author states that it was impossible to clarify relationships because everyone’s surname was Orsós, and there was a high frequency of certain first names too (there were, for example, 10 persons with the name of Orsós János).

The paper cannot be considered a scholarly academic piece as it lacks clear references and the writing style and approach are not always scientific. The author does not draw on scientific and medical records and is not qualified to make assumptions in this field. Furthermore, if the study were to be conducted today there would be clear ethical concerns regarding anonymity and the propriety of methods employed to interview children and interviewees who are illiterate. It should also be noted that such a small study cannot be used to support a broad and general assertion about the cultural habits of Roma, and that a teacher’s perceptions cannot be regarded as scientific fact. It has been reported that Katalin Forray, Professor Emeritus at the Department of Romanology at the University of Pécs, has described the text as being unscientific and containing many generalisations (Magyar Nemzet Online, 2012).

In addition to this, Jeszenszky, in the aforementioned correspondence, makes reference to two other studies as sources for the assertion made in the sentence.

A study about South Wales Gypsies (Williams and Harper, 1977) notes a high incidence of phenylketonuria along with other recessively-inherited disorders and that there was a high degree of consanguinity ($F = 0.017$) with an excess of non-specific mental subnormality among known consanguineous matings. The paper notes that the presence of phenylketonuria and a number of other recessively-inherited disorders has been recorded in other Romany Gypsy populations, but it is uncertain whether this is a result of a generally high gene frequency for the disorders or from consanguinity and other more local factors. Another study referred to in the exchange with Molnár et al. (Thomas, [et al.], 1987) makes reference to medical data on 58 Gypsies in the area of Boston, Massachusetts. Thirteen of twenty-one marriages were consanguineous, yielding an inbreeding coefficient of 0.017. The analysis suggests that both heredity and environment influence the striking pattern of vascular disease in American Gypsies. As Professor Hancock has concluded, reference in these papers is being made to consanguinity, and not to incest, and the authors of the paper use terms such as ‘suggest’ or ‘uncertain’ to convey and describe their conclusions, which certainly do not support any claims that Roma culture sanctions incest.

The studies referred to above were based on small samples and in some cases are now rather dated, being based on data collected over twenty years ago. The communities on which the studies were based were generally isolated through economic, social and spatial exclusion, and or distanced themselves from those outside the group. Consanguinity (cousin marriage) is a trait found in a range of closed and spatially excluded communities, not just Roma minorities and was common amongst the royal families of Europe.

In a letter from Géza Jeszenszky to the World Artists Initiative “Khetanes” (dated 6th November, 2012), reference is made to a World News report in 2008 where Ivo Kremensky, then head of the National Genetic Laboratory and head of the Center for Molecular Medicine Bulgaria, is reported as stating that the number of genetic diseases has increased among Roma people mainly because of incestuous relations (World News, 2008). The commission contacted Professor Kremensky and he expressed surprise at the way he had been cited and stated:

There are no scientific data and I definitely do not support the thesis that you are citing... Apparently I have been cited incorrectly, referring to a text written by a journalist. There has been either misunderstanding or a problem with the translation from Bulgarian. I have not spoken about incestuous relations at all, but about consanguineous marriages, that are known

to increase the risk for some autosomal recessive genetic disorders.

According to Gabriková ([et al.], 2012), over recent decades geneticists have shown growing interest in Roma. Apparently the Roma are considered a valuable target for gene mapping and population studies due to their remarkable migration history, genetic isolation, high rate of consanguinity and existence of multiple subisolates. From a review of the literature it is evident that Professor Kremensky has been an active researcher in this field. A number of Kremensky's journal articles were reviewed by the commission; his research has centred on health issues such as spinal muscular atrophy (Jordanova, [et al.], 2002), GM1-gangliosidosis (Sinigerska, [et al.], 2006), sphingomyelinase-deficient Niemann-Pick disease (Mihaylova, [et al.], 2007) and Wilson's Disease (Mihaylova [et al.], 2007). In discussions on genetic health issues his papers discuss group isolation and endogamy but no reference is made to incestuous relations. Where endogamy is discussed in detail by Kremensky and others (Jordanova, [et al.], 2002) it is amongst first and second cousins.

Kalaydjieva ([et al.], 2001) in a review of the genetic studies on Roma note that studies conducted over the last decade have resulted in the identification of a number of novel single gene disorders and disease-causing mutations (mendelian disorders), and with reference to consanguinity the authors make the following point:

The emphasis on consanguinity in affected families displaces the focus from an obvious need for public health intervention to patterns of personal behaviour. In the face of the reported high gene frequencies, consanguinity is no more relevant than it would be as a cause of beta-thalassemia in Mediterranean countries. High gene frequencies may result in the parallel segregation of phenotypically similar but genetically distinct disorders within the same kindred. This clustering should be borne in mind in diagnostic studies, where assumptions based on pedigree structure should be avoided and independent clinical and genetic assessment should be conducted in all cases.

Where higher rates of mental or physical ill health exist amongst Romani communities it is primarily caused by poverty and poor access to services as demonstrated by a range of studies. An important study on Roma health status in Bulgaria, Hungary and Romania by Masseria ([et al.], 2010) found the main determinants of inequalities in health status in all three countries are education

and wealth, while the role of ethnicity varies across countries and indicators. This suggests that in the regions studied, policies oriented to reducing poverty, improving housing conditions and expanding access to education among the whole population may also serve to mitigate the inequality in health between the national majority population and ethnic minorities, including the Roma. Research by Karlsen and Nazroo (2002) indicates that direct experience of racism has been shown to be associated with poor mental and physical health status. Furthermore, McKenzie (2003) argues that simply feeling vulnerable to experiences of racism may be associated with poorer health.

Rechel ([et al.], 2009) note that Roma children are often enrolled in segregated schools or schools designed for mentally and physically disabled children. The commission contacted Dr Viviane Kovess-Masfety of the Paris Descartes University Research Unit who has led a research project on the mental health of children in Europe, which included analysis of Roma children in Bulgaria and Romania. In the opinion of Dr Kovess-Masfety there exists a vicious circle: Roma children do not have access to adequate teaching and are relegated to low standard schools so they have low school achievement and they are considered to be intellectually disabled.

The signatories to this academic note believe that researchers need to take care with the topic of Roma health and avoid statements which might be misinterpreted or used to pathologise the belonging to or association with Gypsy, Roma and Traveller communities. Statements and reports on Roma health matters need to be based on and refer to scientific and recognized scholarly expertise. We hope this note gives balance and clarity to a debate that became somewhat clouded in the heat of the argument.

REFERENCES

- Budapest Times (2012a) Jeszenszky 'sorry', accessed 29th June 2013, available at: <http://www.budapesttimes.hu/2012/11/29/jeszenszky-sorry/>
- Budapest Times (2012b) Ambassador slams uni for abandoning him amid racism allegations, accessed 29th June 2013, available at: <http://www.budapesttimes.hu/2012/11/14/ambassador-slams-uni-for-abandoning-him-amid-racism-allegations/>
- Budapest (2012), Jeszenszky defended against racism charge, accessed 29th June 2013, available at: <http://budapost.eu/2012/11/jeszenszky-defended-against-racism-charge/>
- Csermely, Péter. (2012) Egy cigány, egy király, Magyar Nemzet Online, accessed 29th June 2013, available at: <http://mno.hu/vezercikk/egy-cigany-egy-kiraly-1115023/>
- Gabriková, Dana [et al.] (2012) 'Unique frequencies of HFE gene variants in Roma /

- Gypsies', *Journal of Applied Genetics*, 53(2): 183 – 187
- Hajioff, Steve-McKee, Martin (2000), 'The health of the Roma people: a review of the published literature', *Journal of Epidemiology and Community Health*, 54(11): 864 – 869
- Jeszszsky, **Géza** (2005), *The New (Post-Communist) Europe and Its Ethnic Problems*, Kairosz Kiadó, Budapest
- MagyarNemzetOnline(2012), Jeszszsky-jegyzet: hazudott a Pécsi Tudományegyetem professzora, accessed 29th June 2013, available at: <http://mno.hu/belfold/jeszszsky-jegyzet-hazudott-a-pecsi-tudomanyegyetem-professzora-1116040>
- Jordanova, Albená [et al.] (2002) 'Spinal muscular atrophy among the Roma (Gypsies) in Bulgaria and Hungary', *Neuromuscular Disorders*, 12: 378 – 385
- Kalaydjieva, Luba [et al.] (2001) 'Genetic studies of the Roma (Gypsies): a review', *BMC Medical Genetics*, 2(5)
- Karlsen, Saffron - Nazroo, James. (2002) 'Relation Between Racial Discrimination, Social Class, and Health Among Ethnic Minority Groups', *Journal of Public Health*, 92(4): 624 – 631
- Martínez-Frias, María - Bermejo, Eva. (1992), 'Prevalence of congenital anomaly syndromes in a Spanish gypsy population', *Journal of Medical Genetics*, 29: 483 – 486
- Masseria, Cristina [et al.] (2010) 'The socio-economic determinants of the health status of Roma in comparison with non-Roma in Bulgaria, Hungary and Romania', *European Journal of Public Health*, 20(5): 549 - 554
- McKenzie, Kwame (2003), 'Racism and health: antiracism is an important health issue', *British Medical Journal*, 326: 65 – 66
- Mihaylova, Violeta [et al.] (2007) 'Highly variable neural involvement in sphingomyelinase-deficient Niemann-Pick disease caused by an ancestral Gypsy mutation', *Brain*, 130:1050 – 1061
- Mihaylova, Violeta [et al.] (2007) 'Wilson's disease in two consecutive generations in a Bulgarian Roma family', *Journal of Neurology*, 254(10): 1462 – 1463
- Nirenberg, Jud (2011), *Gypsy Sexuality: Romani and Outsider Perspectives on Intimacy*, Clambake Press, Arizona
- Politics. Hu (2012) Uproar over ambassador's comments on Roma, accessed 29th June 2013, available at: <http://www.politics.hu/2012/1031/uproar-over-ambassadors-comments-on-roma/>
- Rechel, Boika [et al.] (2009), 'Access to health care for Roma children in Central and Eastern Europe: findings from a qualitative study in Bulgaria', *International Journal for Equity in Health*, 8(24)
- Saggar, Anand – Bittles, Alan (2008) 'Consanguinity and child health'. Occasional review, *Elsevier Paediatrics and child health* 18: 5
- Sinigerska, Ivanka [et al.] (2006) 'Founder mutation causing infantile GM1-gangliosidosis in the Gypsy population', *Molecular Genetics and Metabolism*, 88: 93 – 95
- Thomas, James., [et al.] (1987) 'Disease, lifestyle and consanguinity in 58 American Gypsies', *The Lancet*, 2:377 – 379

- Várnagy, Elemér (ed.) (1994), *Tanulmányok a romológia köréből X.*, Janus Pannonius Tudományegyetem, Pécs
- Williams, Mair–Harper, Peter (1977) ‘Genetic study of Welsh gypsies’ *Journal of Medical Genetics*, 14(3): 172–176
- World News (2008), *Incest Among Roma People Increases Genetic Disease Cases*, accessed 29th June 2013, available at: http://article.wn.com/view/2008/05/21/Incest_Among_Roma_People_Increases_Genetic_Disease_Cases/

CORRESPONDENCE

A letter of protest to Geza Jeszenszky was drafted by Peter Molnar and co-signatories Ian Hancock and Frank Mugisha and led to a response by Jeszenszky and further protest letters such as the one drafted by the World Artists Initiative “Khetanes”. Correspondence from Géza Jeszenszky to the World Artists Initiative “Khetanes”, 6th November, 2012

The above correspondence can be accessed at: http://artists-for-roma-net.ning.com/profiles/blog/show?id=6323259%3ABlogPost%3A53696&commentId=6323259%3AComment%3A54073&xg_source=activity