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7 The Prevalence of Disability among Roma
8 and non-Roma Children in Four West
9 Balkan Countries

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12 **Key words**

13 Disability, Roma, Children, Middle-income countries, MICS, UNICEF

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16 Abstract

17 Background

18 Very little is known about the prevalence of disability among Roma children.

19 Objective

20 To estimate the prevalence of disability among Roma and non-Roma children in four West Balkan
21 countries.

22 Methods

23 Secondary analysis of data collected in Round 6 of UNICEF's Multiple Indicators Cluster Surveys.
24 Nationally representative samples of 6,290 Roma and 13,005 non-Roma children in Kosovo,
25 Montenegro, the Republic of North Macedonia and Serbia.

26 Results

27 Roma children were twice as likely to have a disability than their peers and were more likely to have
28 functional limitations in all but one of the domains investigated. Adjusting risk estimates to take
29 account of between-group differences in household wealth and maternal education led to modest
30 attenuation of effect sizes for risk of disability.

31 Conclusions

32 Disability is significantly more prevalent among Roma children than among their non-Roma peers in
33 four Western Balkan countries. Future research should focus on the extent to which differences in
34 disability may be attributable to differential rates of exposure to a wider range of social
35 determinants.

36

37 Introduction

38 Social and public health policy aimed at addressing inequities in health and wellbeing has
39 increasingly emphasised the importance of paying specific attention to issues facing groups that are
40 particularly marginalised or vulnerable. For example, the *2011 Rio Political Declaration on Social*
41 *Determinants of Health* called on governments to ‘develop policies that are inclusive and take
42 account of the needs of the entire population *with specific attention to vulnerable groups* and high-
43 risk areas’ [emphasis added].¹ The *WHO Review of Social Determinants and the Health Divide in the*
44 *WHO European Region* called on governments to ‘take action to develop systems and processes
45 within societies that are more sustainable, cohesive and inclusive, *focusing particularly on groups*
46 *most severely affected by exclusionary processes*’ [emphasis added].² Two of the marginalised groups
47 highlighted in the *WHO Review* were Roma peoples and people with disabilities.

48 As the *WHO Review* explains ‘the term Roma is used widely to describe highly heterogeneous groups
49 of people who may describe themselves as Roma, Gypsies, Travellers, Manouches, Ashkali, Sinti and
50 other titles’.² With an estimated population of approximately 10-12 million, they constitute the
51 largest minority ethnic community in Europe.²⁻⁴ The *WHO Review* concluded that ‘Roma across the
52 Region are exposed to powerful social, economic, political and cultural exclusionary processes
53 (including prejudice and discrimination) that negatively affect their human rights and restrict their
54 self-determination [and that] this situation is leading to gross inequities in health and well-being
55 among Roma compared to other populations’.²

56 While the evidence that does exist suggests that the health needs of the Roma population are
57 considerable,⁵⁻⁸ most reviews have also drawn attention to significant gaps in the evidence base
58 (e.g., the limited number of studies that have focused on children or reported on non-communicable
59 disease) and the low methodological quality of many studies (e.g., the use of convenience samples
60 and the common absence of non-Roma comparison groups).⁵⁻⁸

61 In particular, very little attention has been paid to the extent of disability among Roma populations.⁷

62 ⁸ While the existing literature suggests a higher prevalence among Roma of health conditions or
63 impairments that are commonly associated with disability (e.g., congenital disorders,^{9,10} Type 2
64 diabetes and metabolic syndrome,¹¹ obesity,⁸ chronic condition among adults¹²), very few scientific
65 papers have reported on the extent to which people experience limitations in their everyday
66 activities or social participation. The exceptions suggest that higher rates of functional limitations
67 exist among: Roma children and adults in Hungary;¹³ Roma women aged 30-64 in Hungary;¹⁴ and
68 adult Roma of Irish origin in England.¹⁵ In contrast, the UNDP/World Bank/EC Regional Roma Survey
69 (undertaken in 12 Central European countries) reported no difference between Roma and non-Roma
70 adults in the prevalence of activity limitations due to a health problem during the last 6 months.¹⁶

71 Without prevalence of disability data for children with disability and significant cognitive delay
72 compared to their non-disabled peers, the nature and extent of the interventions that may be
73 required to overcome the likely loss of their developmental potential cannot be determined.¹⁷

74 The primary aim of the present paper is to partially redress this omission by estimating the
75 prevalence of disability and significant cognitive delay among Roma and non-Roma children in four
76 West Balkan countries.

77

78 Method

79 We undertook secondary analysis of nationally representative data collected in Round 6 (2017-) of
80 UNICEF's Multiple Indicator Cluster Surveys (MICS6).¹⁸ Following approval by UNICEF, MICS6 data
81 were downloaded from <http://mics.unicef.org/>. MICS6 contains several questionnaire modules. Data
82 used in the present paper were extracted from the household module, the module applied to all
83 children under five living in the household and the module applied to a randomly selected child age
84 5-17 living in the household.¹⁹ All participating countries used cluster sampling methods to derive
85 samples representative of the national population of mothers and young children. In previous waves
86 of MICS a small number of countries in the West Balkans undertook in parallel national surveys of
87 Roma populations. In MICS 4 or 5, for example, Roma-specific surveys were undertaken in Bosnia
88 and Herzegovina, Kosovo (under UNSC resolution 1244), Montenegro, North Macedonia and Serbia.
89 In MICS6 four of these Western Balkan countries (Kosovo, Montenegro, the Republic of North
90 Macedonia and Serbia) collected data on representative samples of children living in Roma
91 households. Specific details of the sampling procedure and the procedures used for ethical review in
92 each country are available in Country Reports available at <http://mics.unicef.org/>.²⁰⁻²³

93 Child Disability

94 MICS6 contained two new modules (one for 2-4-year-old children, the other for 5-17-year-old
95 children) to identify children with disabilities. Developed by the Washington Group on Disability
96 Statistics (WGDS: <http://www.washingtongroup-disability.com/>), the modules were based on
97 informant report of child difficulties in nine functional domains for children aged 2-4 (seeing,
98 hearing, walking, fine motor, understanding, being understood, learning, playing, controlling
99 behaviour) and 14 domains for children 5-17 (seeing, hearing, walking, self-care, being understood
100 inside the household, being understood outside the household, learning, remembering, focusing,
101 accepting change, making friends, anxiety, depression, controlling behaviour). Four response options
102 were available for all domains other than the anxiety, depression and behaviour domains ([1] 'no

103 *difficulty*, [2] *'some difficulty*', [3] *'a lot of difficulty*', [4] *'cannot do at all'*). The controlling behaviour
104 domain had five response options ([1] *'not at all'*, [2] *'less'*, [3] *'the same'*, [4] *'more'* or [5] *'a lot*
105 *more'*) as did the anxiety and depression domains ([1] *'daily'*, [2] *'weekly'*, [3] *'monthly'*, [4] *'a few*
106 *times a year'*, [5] *'never'*).

107 Following Initial validation of the new modules in three low/middle income countries the WGDS
108 recommended defining disability as having at least *'a lot of difficulty'* in one or more domains or
109 having *'daily'* problems with either anxiety or depression or having *'a lot more difficulty'* in
110 controlling behaviour. We used recommended WGDS cut-off to define child disabilities and child
111 disabilities associated with the specific functional limitations listed above.

112 In addition, we created a separate binary variable of multiple disability (at least *'a lot of difficulty'* in
113 two or more areas; reference group no disability). Within the multiple disability group, the strongest
114 associations between functional impairments ($r \geq +0.400$) were between anxiety and depression,
115 controlling behaviour and concentrating/making friends/speech, concentrating and accepting
116 change/remembering/self-care/speech, hearing and understanding, learning and
117 speech/remembering, walking and playing/self-care/fine motor skills, and self-care and speech.

118 For all disability measures the reference group was children without disabilities. Disability data were
119 missing for 1.1% of children.

120 Significant Cognitive Delay

121 The child under five module also contained the Early Child Development Index (ECDI), a ten item
122 scale with four domains (literacy-numeracy; physical; social emotional; and learning), each item
123 being based on milestones that children are expected to achieve by age 3/4.²⁴ ECDI data were
124 collected for children in the age range 36-59 months. We used the procedure outlined by Emerson
125 et al to identify children with significant cognitive delay (SCD) as a failure to score positively on any
126 of the five items in the literacy-numeracy and learning domains.^{25, 26} All items were based on key
127 informant report with simple binary (yes/no) response options.

- 128 • *Literacy-numeracy*: Can the child: (1) identify/name at least ten letters of the alphabet; (2)
129 read at least four simple, popular words; (3) name and recognize the symbols of all numbers
130 from 1 to 10?
- 131 • *Learning*: Can the child: (4) follow simple directions on how to do something correctly; (5)
132 when given something to do, do it independently?

133 The five items demonstrated a modest internal consistency across the whole sample ($\alpha=0.51$).

134 SCD data were missing for 1.1% of children.

135 Household Wealth

136 Household wealth is likely to be associated with the prevalence of child disability.^{27, 28} MICS6 data
137 includes a within-country wealth index for each household based on the assets owned by that
138 household weighted by principal component factors scores. The wealth index is assumed to capture
139 underlying long-term wealth through information on the household assets.²⁹⁻³² These data were
140 collected in all countries. Data were complete for all children.

141 Maternal Education

142 Level of maternal education is also likely to be associated with the prevalence of child disability.²⁷
143 MICS data records the highest level of education received by the child's mother was recorded using
144 country-specific categories. Following the procedures used by Emerson and colleagues, we recoded
145 these data into a three-category measure: (1) no education; (2) primary education; (3) receipt of
146 secondary or higher-level education.^{25, 33} These data were collected in all countries. Data were
147 missing for 0.2% of children.

148 Approach to Analysis

149 All analyses were undertaken in Stata 16.1. In the first stage of analysis, we used simple bivariate
150 descriptive statistics to estimate the prevalence of child disability and significant cognitive delay
151 among children growing up in Roma households and children growing up in non-Roma households

152 (with 95% confidence intervals) for each country. Prevalence estimates were calculated using the
153 svyset/svy routines to take account of the clustered sample designs. In the second stage of analysis,
154 we used mixed effects multilevel modelling to estimate the risk of child disability and including
155 significant cognitive delay among children growing up in Roma households (children growing up in
156 non-Roma households being the reference group). Mixed effects multilevel modelling using Poisson
157 regression of within-country associations were fitted in Stata using the mepoisson command to
158 generate adjusted prevalence rate ratios (adjusted relative risk).³⁴ Random effects were specified to
159 allow the slope and intercept of the relationship between Roma status and disability to vary across
160 countries. Two versions of the adjusted prevalence rate ratios are reported: Model 1 adjusts for
161 basic child demographics (age, gender); Model 2 also adjusts for differences in the child's living
162 situation (household wealth and level of maternal education). Adjusting for basic child demographics
163 is important as disability is generally more common among boys and increases with child age.³⁵
164 Additionally, adjusting for between group differences in living situation is important as (as noted
165 above) indicators of the living situation of children growing up in Roma settlements differ markedly
166 from that of their non-Roma peers in ways that may be detrimental to their health and wellbeing.²⁻⁴
167 UNICEF's country-specific child-level weights were used to take account of biases in sampling frames
168 and household and individual level non-response. Given the small amount of missing data, complete
169 case analyses were undertaken.

170

171 Results

172 Information on response rates and sample sizes are presented in Table 1. Prevalence estimates for
173 each country for disability and significant cognitive delay are presented in Table 2. As can be seen,
174 prevalence rates for: (1) disability were higher among Roma for all eight comparisons, significantly so
175 for seven; (2) SCD were higher among Roma for all four comparisons, significantly so for two. Data
176 aggregated across the four countries indicated that children with SCD were ten times more likely to
177 have a disability (APRR=10.43(5.99-18.18) $p<0.001$), and 66 times more likely to have a functional
178 limitation associated with learning (APRR=66.22(53.65-81.73) $p<0.001$) than children without
179 significant cognitive delay.

180 Adjusted prevalence rate ratios pooled across the four countries are presented in Table 3 for
181 disability, multiple disability, significant cognitive delay and each form of functional limitation
182 associated with disability. In Table 3 the order of functional limitations associated with disability in
183 each age group reflects overall prevalence rates (from most to least prevalence).

184 When compared with non-Roma children, Roma children under five were just over twice as likely to
185 have a disability, four times more likely to have multiple disabilities and over 5 times more likely to
186 have significant cognitive delay when risk was adjusted for between group differences in age and
187 gender (Table 3). They were also more likely to have functional limitations in eight of the nine
188 domains investigated, significantly so in five domains. When compared with non-Roma children,
189 Roma children aged five to 17 were over twice as likely to have a disability and to have multiple
190 disabilities when risk was adjusted for between group differences in age and gender (Table 3). They
191 were also more likely to have functional limitations in all 14 domains investigated, significantly so in
192 13 domains. When these analyses were further adjusted to take account of between-group
193 differences in relative household wealth and maternal level of education, risk of disability and
194 multiple disability was reduced by 0% and 34% respectively for Roma children under five and by 5%
195 and 25% respectively for Roma children aged five to seventeen.

196 Among 5-17-year-old Roma and non-Roma children with disability, by far the most prevalent
197 impairments associated with disability were anxiety (63.5% (95% CI 58.4%-68.3%) and depression
198 (23.7% (95% CI 20.4%-27.3%).

199

200 Discussion

201 Our analyses (based on nationally representative samples of 6,290 Roma and 13,005 non-Roma
202 children indicated that: (1) Roma children under five were just over twice as likely to have a
203 disability, four times more likely to have multiple disabilities and five times more likely to have
204 significant cognitive delay than their peers when the risk was adjusted to take account of between
205 group differences in age and gender, and were more likely to have functional limitations in eight of
206 the nine domains investigated; (2) Roma children five and older were over twice as likely to have a
207 disability and multiple disabilities than their peers when the risk was adjusted to take account of
208 between group differences in age and gender, and were more likely to have functional limitations in
209 all 14 of the domains investigated; (3) further adjusting risk estimates to take account of between-
210 group differences in household wealth and level of maternal education led to marked attenuation of
211 effect sizes for risk of multiple disabilities for Roma children.

212 Our results add significantly to the existing evidence base on Roma wellbeing in three important
213 ways. First, they are one of the few studies published to date that report on the extent of disability
214 among Roma and non-Roma children. Second, they add to the sparse literature on the prevalence of
215 non-communicable disease among Roma children. Third, the sampling strategies used to generate
216 nationally representative samples of Roma and non-Roma children with high response rates avoid
217 some of the key methodological shortcomings that characterise much of the existing literature on
218 Roma health.

219 Our results need to be considered in the context of several limitations. First, our ability to adjust risk
220 estimates to take account of differential exposure to well-established social and environmental
221 determinants of poor health was limited to just two variables (relative household wealth and level of
222 maternal education). Inclusion of a wider range of variables (e.g., exposure to violence,
223 discrimination, poor housing conditions, environmental pollutants) may have resulted in a more
224 marked attenuation of risk.^{2-4, 36, 37} Second, child disability was determined solely by parental report.

225 While such a procedure is understandable for younger children, the failure to include self-report
226 formats for older children/adolescents can be considered problematic given: (1) the importance of
227 children, including those with a disability, having a voice in research;³⁸ and (2) the evidence that the
228 correspondence between child and parental report of child health status is often modest.^{39, 40} Third,
229 given the heterogeneity of Roma populations,² care needs to be taken in generalising the present
230 results to Roma populations in other countries. Finally, most items relating to child disability require
231 the parental informant to make a judgement between the capabilities of their child in relation to
232 children of the same age. Given MICS is attempting to generate nationally representative data, this
233 does require parents to have robust knowledge of the capabilities of children at specific ages in the
234 country in which they live. There is evidence to suggest that this question format can lead to
235 systematic biases involving the under-reporting of disability in poorer households/areas and the
236 over-reporting of disabilities in wealthier households/areas.⁴¹

237 Overall, our results indicate that disability is significantly more prevalent among Roma children than
238 among their non-Roma peers in four Western Balkan countries. Future research is needed to
239 determine; (1) whether the differences for children are also apparent between adult Roma and non-
240 Roma women and men; and (2) the extent to which differences in disability status for children may
241 be attributable to differential rates of exposure to a wider range of social determinants of health.
242 Our results also suggest that attempts to support Roma children in the Western Balkans will need to
243 be sensitive to the importance and impact of disability in relation to such issues as prevention,
244 service delivery and empowerment, and that attempts to break the cycle of the exclusion of Roma
245 children in the Western Balkans³⁶ may need to specifically address the situation of Roma children
246 with disabilities.

247

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251

252 References

- 253 **1.** World Health Organization. *Rio Political Declaration on Social Determinants of Health*
254 (<http://www.who.int/sdhconference/declaration/en/>). Geneva: World Health Organization;
255 2011.
- 256 **2.** World Health Organization Regional Office for Europe. *Report on social determinants and the*
257 *health divide in the WHO European Region: Final Report (updated)*. Copenhagen: World
258 Health Organization Regional Office for Europe; 2014.
- 259 **3.** Commissioner for Human Rights. Human rights of Roma and Travellers in Europe.
260 Strasbourg: Council of Europe; 2013.
- 261 **4.** European Union Agency for Fundamental Rights, UNDP. The situation of Roma in 11 EU
262 Member States: Survey results at a glance. Luxembourg: Publications Office of the European
263 Union; 2012.
- 264 **5.** Hajioff S, McKee M. The health of the Roma people: A review of the published literature.
265 *Journal of Epidemiology & Community Health*. 2000;54:864–869.
- 266 **6.** Fernández-Feito A, Pesquera-Cabezas R, González-Cobo C, Prieto-Salceda MD. What do we
267 know about the health of Spanish Roma people and what has been done to improve it? A
268 scoping review. *Ethnicity & Health*. 2019;24:224-243.
- 269 **7.** Van Dijk JP. Roma health: Do we know enough? *International Journal of Public Health*.
270 2019;64:647–648.

- 271 **8.** Cook B, Wayne GF, Valentine A, Lessios A, Yeh E. Revisiting the evidence on health and
272 health care disparities among the Roma: a systematic review 2003–2012. *International*
273 *Journal of Public Health*. 2013;58:885–911.
- 274 **9.** Koupilova I, Epstein H, Holcik J, Hajioff S, McKee M. Health needs of the Roma population in
275 the Czech and Slovak Republics. *Social Science & Medicine*. 2001;53:1191–1204.
- 276 **10.** Martinez-Frias ML, Bermejo E. Prevalence of congenital anomaly syndromes in Spanish
277 gypsy population. *Journal of Medical Genetics*. 1992;29:483–486.
- 278 **11.** Kosa Z, Moravcsik-Kornyicki A, Dioszegi J, et al. Prevalence of metabolic syndrome among
279 Roma: A comparative health examination survey in Hungary. *European Journal of Public*
280 *Health*. 2015;25:299–304.
- 281 **12.** Masseria C, Mladovsky P, Hernandez-Quevedo C. The socio-economic determinants of the
282 health status of Roma in comparison with non-Roma in Bulgaria, Hungary and Romania.
283 *European Journal of Public Health*. 2010;20:549–554.
- 284 **13.** Vincze F, Földvári A, Pálincás A, et al. Prevalence of Chronic Diseases and Activity-Limiting
285 Disability among Roma and Non-Roma People: A Cross-Sectional, Census-Based
286 Investigation. *Int Journal of Environmental Research & Public Health*. 2019;16:3620.
- 287 **14.** Kosa Z, Szeles G, Kardos L, et al. A comparative health survey of the inhabitants of Roma
288 settlements in Hungary. *American Journal of Public Health*. 2007;97:853–859.
- 289 **15.** Parry G, Van Cleemput P, Peters J, Walters S, Thomas K, Cooper C. Health status of Gypsies
290 and travellers in England. *Journal of Epidemiology & Community Health*. 2007;61:198.
- 291 **16.** Mihailov D. The health situation of Roma communities: Analysis of the data from the
292 UNDP/World Bank/EC Regional Roma Survey 2011. Roma Inclusion Working Papers.
293 Bratislava: United Nations Development Programme; 2012.
- 294 **17.** Emerson E, Llewellyn G. The Circumstances of Children with and without Disabilities or
295 Significant Cognitive Delay Living in Ordinary Households in 30 Middle- and Low-Income
296 Countries. *Disabilities*. 2021;1:174–186.

- 297 **18.** UNICEF. Monitoring the Situation of Children and Women for 20 Years: The Multiple
298 Indicator Cluster Surveys (MICS) 1995–2015. New York: UNICEF; 2015.
- 299 **19.** Khan S, Hancioglu A. Multiple Indicator Cluster Surveys: Delivering Robust Data on Children
300 and Women across the Globe. *Studies in Family Planning*. 2019;50:279-286.
- 301 **20.** Statistical Office of Montenegro (MONSTAT), UNICEF. 2018 Montenegro Multiple Indicator
302 Cluster Survey and 2018 Montenegro Roma Settlements Multiple Indicator Cluster Survey,
303 Survey Findings Report. Podgorica, Montenegro: MONSTAT and UNICEF; 2019.
- 304 **21.** State Statistical Office, UNICEF. 2018-2019 North Macedonia Multiple Indicator Cluster
305 Survey and 2018-2019 North Macedonia Roma Settlements Multiple Indicator Cluster
306 Survey, Survey Findings Report. Skopje, North Macedonia: State Statistical Office and UNICEF;
307 2020.
- 308 **22.** Statistical Office of the Republic of Serbia, UNICEF. Serbia Multiple Indicator Cluster Survey
309 and Serbia Roma Settlements Multiple Indicator Cluster Survey, 2019, Survey Findings
310 Report. Belgrade, Serbia: Statistical Office of the Republic of Serbia and UNICEF; 2019.
- 311 **23.** Kosovo Agency of Statistics, UNICEF. 2019–2020 Kosovo Multiple Indicator Cluster Survey
312 and 2019–2020 Roma, Ashkali and Egyptian Communities Multiple Indicator Cluster Survey,
313 Survey Findings Report. Prishtina, Kosovo: Kosovo Agency of Statistics and UNICEF; 2020.
- 314 **24.** UNICEF. The formative years: UNICEF’s work on measuring early childhood development.
315 New York: UNICEF; 2014.
- 316 **25.** Emerson E, Savage A, Llewellyn G. Significant cognitive delay among 3- to 4-year old children
317 in low- and middle-income countries: prevalence estimates and potential impact of
318 preventative interventions. *International Journal of Epidemiology*. 2018;47:1465–1474.
- 319 **26.** Emerson E, Savage A, Llewellyn G. Prevalence of underweight, wasting and stunting among
320 young children with a significant cognitive delay in 47 low and middle-income countries.
321 *Journal of Intellectual Disability Research*. 2020;64:93-102.

- 322 **27.** Cappa C, Mont D, Loeb M, et al. The Development and Testing of a Module on Child
323 Functioning for Identifying Children with Disabilities on Surveys. III: Field Testing. *Disability*
324 *and Health Journal*. 2018;11:510-518.
- 325 **28.** Banks LM, Kuper H, Polack S. Poverty and disability in low- and middle-income countries: A
326 systematic review. *PLoS One*. 2017;12:e0189996.
- 327 **29.** Rutstein SO. The DHS Wealth Index: Approaches for Rural and Urban Areas. DHS Working
328 Papers No. 60. Calverton, Maryland: Macro International Inc; 2008.
- 329 **30.** Rutstein SO, Johnson K. The DHS Wealth Index: DHS Comparative Reports No. 6. Calverton,
330 Maryland: ORC Macro 2004.
- 331 **31.** Howe LD, Galobardes B, Matijasevich A, et al. Measuring socio-economic position for
332 epidemiological studies in low- and middle-income countries: a methods of measurement in
333 epidemiology paper. *International Journal of Epidemiology* 2012;41:871-886.
- 334 **32.** Poirier MJP, Grépin KE, Grignon M. Approaches and Alternatives to the Wealth Index to
335 Measure Socioeconomic Status Using Survey Data: A Critical Interpretive Synthesis. *Social*
336 *Indicators Research*. 2020;148:1-46.
- 337 **33.** Emerson E, Llewellyn G. The exposure of children with and without disabilities to violent
338 parental discipline: Cross-sectional surveys in 17 middle- and low-income countries. *Child*
339 *Abuse & Neglect*. 2021;111:104773.
- 340 **34.** Rabe-Hesketh S, Skrondal A. *Multilevel and Longitudinal Modelling Using Stata. Volume II:*
341 *Categorical Responses, Counts, and Survival*. 3rd ed. College Station, TX: Stata Press; 2012.
- 342 **35.** Blackburn C, Read J, Spencer N. Prevalence of childhood disability and the characteristics
343 and circumstances of disabled children in the UK: Secondary Analysis of the Family
344 Resources Survey. *BMC Pediatrics*. 2010;10.
- 345 **36.** Robayo-Abril M, Millán N. Breaking the Cycle of Roma Exclusion in the Western Balkans.
346 Washington, DC: World Bank; 2019.

- 347 **37.** Regional Cooperation Council. Balkan Barometer 2020. Sarajevo: Regional Cooperation
348 Council; 2020.
- 349 **38.** Weil LG, Lemer C, Webb E, Hargreaves DS. The voices of children and young people in
350 health: where are we now? *Archive of Diseases of Childhood*. 2015;100:915-917.
- 351 **39.** Eiser C, Morse R. Can parents rate their child's health-related quality of life? Results of a
352 systematic review. *Quality of Life Research* 2001;10:347-357.
- 353 **40.** Arman S, Amel AK, Maracy MR. Comparison of parent adolescent scores on Strengths and
354 Difficulties Questionnaire. *Journal of Research in Medical Sciences*. 2013;18:501–505.
- 355 **41.** Emerson E, Llewellyn G. Identifying children at risk of intellectual disability in UNICEF's
356 multiple indicator cluster surveys: cross-sectional survey. *Disability and Health Journal*. 2021
357 14:100986.

Table 1: Survey Details by Country					
	Year of survey	Response rate		Sample size	
		Children age 2-4	Children age 5-17	Children age 2-4	Children age 5-17
<i>Kosovo</i>					
Roma	2019/20	85.7%	86.6%	335	517
National	2019/20	78.2%	80.1%	1,813	2,353
<i>Montenegro</i>					
Roma	2018	63.7%	63.3%	341	466
National	2018	60.7%	60.5%	673	2,012
<i>North Macedonia</i>					
Roma	2018/19	90.0%	91.8%	424	1,505
National	2018/19	86.3%	86.8%	921	1,476
<i>Serbia</i>					
Roma	2019	92.6%	94.0%	649	2,053
National	2019	79.5%	80.8%	1,110	2,647
Note: Sample sizes are weighted and only include participants for who valid data on disability status are available					

Table 2: Country Prevalence Estimates for Disability and Significant Cognitive Delay			
	Disability (age 2-4)	Significant Cognitive Delay (age 3-4)	Disability (age 5-17)
<i>Kosovo</i>			
Roma	5.0% (2.8-8.8)	6.4%*** (3.2-12.3)	16.8%*** (12.6-21.9)
National	3.2% (2.1-4.7)	0.8% (0.3-2.0)	8.7% (7.3-10.4)
<i>Montenegro</i>			
Roma	2.9%** (1.6-5.3)	6.7%** (4.0-10.9)	30.5%*** (26.5-34.8)
National	0.6% (0.2-1.8)	1.2% (0.3-4.7)	7.6% (5.4-10.7)
<i>North Macedonia</i>			
Roma	5.6%*** (3.8-8.3)	3.3% (1.8-5.9)	24.4%*** (19.5-30.0)
National	1.4% (0.7-2.6)	1.3% (0.5-2.9)	11.3% (8.5-14.7)
<i>Serbia</i>			
Roma	2.9%* (1.8-4.5)	0.3% (0.1-1.5)	14.0%*** (11.2-17.4)
National	1.6% (1.0-2.4)	0.0% (0.0-0.5)	4.9% (3.6-6.7)
Note: Prevalence significantly greater (design-based F) * p<0.05, ** p<0.01, *** p<0.001			

Table 3: Pooled adjusted prevalence rate ratios for disability, each form of functional limitation associated with disability and significant cognitive delay for children age 2-4 and age 5-17				
	Prevalence		Adjusted Prevalence Rate Ratios	
	Roma	National	Model 1	Model 2
Children age 2-4				
Significant cognitive delay	3.4% (2.2-5.4)	0.8% (0.4-1.4)	5.34*** (3.15-9.08)	3.74** (1.49-9.38)
Disability	4.0% (3.1-5.1)	2.0% (1.5-2.7)	2.29** (1.32-3.96)	2.29** (1.27-4.13)
Multiple Disability	1.4% (0.9-2.0)	0.3% (0.2-0.6)	4.01*** (2.51-6.42)	2.64** (1.38-5.05)
Functional limitations (as defined in WGDS modules) associated with ...				
Being understood	1.7% (1.0-2.8)	1.0% (0.7-1.5)	2.08*** (1.65-2.62)	2.70*** (1.87-3.90)
Learning	1.2% (0.7-2.1)	0.8% (0.5-1.2)	1.60** (1.20-2.13)	1.51 (0.60-3.83)
Controlling behaviour	0.7% (0.4-1.2)	0.6% (0.3-0.9)	1.45 (0.31-6.91)	1.56 (0.31-8.00)
Seeing	0.7% (0.4-1.3)	0.3% (0.1-0.6)	2.52* (1.10-5.74)	1.32 (0.36-4.82)
Playing	0.7% (0.4-1.2)	0.3% (0.2-0.6)	2.12 (0.85-5.29)	2.12 (0.46-9.82)
Fine motor	0.2% (0.1-0.5)	0.3% (0.1-0.6)	0.69 (0.20-2.44)	0.55 (0.09-3.50)
Understanding	0.8% (0.5-1.4)	0.2% (0.1-0.4)	4.88*** (3.13-7.63)	6.08*** (1.74-21.26)
Walking	0.4% (0.2-0.8)	0.1% (0.1-0.4)	2.47 (0.60-10.17)	1.23 (0.30-4.99)
Hearing	0.4% (0.2-0.8)	0.0% (0.0-0.2)	9.67** (2.31-40.39)	9.41** (2.42-36.54)
Children age 5-17				
Disability	19.4% (16.4-22.9)	7.7% (6.8-8.8)	2.24*** (1.95-2.57)	2.13*** (1.48-3.07)
Multiple Disability	8.6% (7.1-10.4)	2.6% (2.1-3.2)	2.77*** (1.72-4.43)	2.08** (1.21-3.58)
Functional limitations (as defined in WGDS modules) associated with ...				
Anxiety	12.4% (9.7-15.8)	5.0% (4.2-5.9)	3.11*** (2.21-4.36)	2.45*** (1.90-3.17)
Depression	4.9% (3.8-6.2)	1.7% (1.3-2.2)	2.86*** (2.07-3.97)	2.04*** (1.73-2.40)
Accepting change	1.1% (0.7-1.6)	1.0% (0.7-1.4)	1.29 (0.41-4.01)	0.95 (0.29-3.13)
Learning	4.1% (2.9-5.6)	0.9% (0.6-1.4)	2.89** (1.39-5.99)	2.18* (1.04-4.58)
Making friends	1.4% (0.9-2.1)	0.8% (0.6-1.3)	1.75** (1.19-2.56)	1.99*** (1.47-2.69)

Walking 500m	1.4% (1.0-1.9)	0.7% (0.5-1.0)	2.04* (1.04-3.99)	1.64 (0.81-3.31)
Remembering	2.4% (1.6-3.5)	0.6% (0.4-0.9)	3.48*** (1.76-6.85)	1.45 (0.88-2.40)
Concentrating			1.91*** (1.57-2.31)	0.75 (0.25-2.28)
Being understood outside the household	1.0% (0.7-1.5)	0.5% (0.4-0.8)	1.79* (1.01-3.47)	1.20 (0.56-2.59)
Being understood inside the household	0.8% (0.4-1.3)	0.4% (0.2-0.6)	2.12*** (1.41-3.18)	1.50 (0.88-2.56)
Self-care	0.7% (0.4-1.1)	0.4% (0.2-0.6)	1.61* (1.00-2.57)	1.07 (0.64-1.81)
Seeing	0.9% (0.5-1.6)	0.2% (0.1-0.5)	3.42* (1.27-9.28)	3.36** (1.46-7.73)
Hearing	0.1% (0.0-0.3)	0.0% (0.0-0.1)	5.86* (1.27-27.06)	10.03 (0.94-106.70)
Controlling behaviour	2.1% (1.4-3.0)	0.6% (0.4-0.9)	3.52*** (2.85-4.34)	2.01*** (1.64-2.46)
<p>Note: * p<0.05, ** p<0.01, *** p<0.001 Model 1: Adjusted for child age and gender Model 2: Also adjusted for relative household wealth and highest level of maternal education.</p>				