

“Social Exclusion, disadvantage, vulnerability and health inequalities”

A task group supporting the Marmot region review of social determinants  
of health and the health divide in the EURO region

## **Background Paper 5**

### **Health Inequalities and People with Disabilities in Europe**

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## Summary

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It has recently been estimated that 15-19% of the world's population are disabled.<sup>1</sup> In this report we have summarised current knowledge about the extent and determinants of the health inequalities faced by disabled people across Europe.

Our analyses of World Health Survey data (in which 12% of people were identified as disabled) suggests that the prevalence of disability in Europe increases with age, gender (higher rates being reported among women), lower national wealth, increased within-country income inequality and lower within-country socio-economic position. It also revealed the widespread risk of poorer health among disabled people in relation to major public health issues (obesity) and aspects of health that are unlikely to be directly associated with the health condition or impairments associated with disability (oral health).

We have drawn attention to four general factors which underlie these inequalities, each of which is amenable to intervention:

- Some health conditions or impairments associated with disability involve increased risk of 'secondary' health conditions or impairments;
- Exposure to well established 'social determinants' of (poorer) health independently increases the risk of health conditions or impairments associated with disability and poor health;
- Disability discrimination increases the risk of exposure to well established 'social determinants' of (poorer) health;
- Disability discrimination reduces access to health information as well as timely and effective health care.

In response to these observations we have made four overarching recommendations:

1. For all the countries in the European region to ratify and implement the United Nations Convention on the Rights of Persons with Disabilities;
2. That the *Review* establishes an Equality Impact Assessment Panel (which would include a representative of Disabled People's Organisations across Europe) to consider for each recommendation made in the final report:
  - a. The likely impact of the recommendation on marginalised or disadvantaged groups (including people with disabilities);
  - b. What specific modifications or adjustments need to be made to ensure that marginalised or disadvantaged groups (including people with disabilities) experience equal benefits from the proposed initiative.

3. That each country adopts an action plan for reducing inequality in health faced by people with disabilities. This action plan should make specific reference to progress planned on the phasing out and closure of institutional forms of residential and day-service provision.
4. That the European Regional Office of WHO convene a meeting in 2013 or 2014 to review progress and share experience on reducing health inequalities faced by disabled people across the region.

Our recommendations are designed to build on existing initiatives to reduce health inequalities by making them more sensitive to the situation of disabled people, and by linking existing initiatives to current developments in international disability policy and legislation.

## Understanding Disability

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Disability is often a vigorously contested concept. According to the UN Convention on the Rights of Persons with Disabilities (CRPD) the concept includes ‘...those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.’ (CRPD Article 1).

Over recent decades our understanding of disability has moved from one in which the social exclusion faced by people with particular health conditions or impairments was seen as the inevitable consequences of ill health (often referred to as a ‘medical’ or ‘individual’ model of disability) to one in which they are seen as being powerfully shaped by social structures and socio-cultural practices (often referred to as a ‘social model’ of disability).<sup>2-6</sup> Within the latter framework, disability is not viewed as an inherent characteristic of individuals, but the result of the interaction between impairments and discriminatory socio-cultural practices to which people with particular health conditions or impairments may be exposed. As such, disability is being increasingly seen as a human rights issue, which was further stressed with the adoption of the CRPD in 2006.<sup>1 7-10</sup>

As stated in the World Report on Disability, ‘*disability is a human rights issue because:*

- *People with disabilities experience inequalities – for example, when they are denied equal access to health care, employment, education, or political participation because of their disability.*
- *People with disabilities are subject to violations of dignity – for example, when they are subjected to violence, abuse, prejudice, or disrespect because of their disability.*
- *Some people with disability are denied autonomy – for example, when they are subjected to involuntary sterilization, or when they are confined in institutions against their will, or when they are regarded as legally incompetent because of their disability.’<sup>1</sup>*

It is in light of these potential violations of human rights that, as of 1<sup>st</sup> August 2012, the European Union and all but three<sup>a</sup> of the 53 Member States of the WHO European Region are signatories to the UN Convention on the Rights of persons with Disabilities and that 34 Member States and the European Union have ratified the Convention.<sup>b</sup> The Convention seeks ‘to promote, protect and ensure the full and

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<sup>a</sup> Belarus, Switzerland and Tajikistan

<sup>b</sup> Armenia, Austria, Azerbaijan, Belgium, Bosnia and Herzegovina, Bulgaria, Croatia, Cyprus, Czech Republic, Denmark, Estonia, France, Germany, Greece, Hungary, Italy, Latvia, Lithuania, Luxembourg,

equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.’<sup>8</sup>

The CRPD focuses on the various policy sectors of society and is thus relevant for all the social determinants of health explaining the poorer health experienced by people with disabilities. The convention also includes an article specifically on health, confirming that “...persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability”. (CRPD, article 25)

The changes in understanding of disability are also reflected in the WHO’s current approach to the classification of disability; the *International Classification of Functioning, Disability and Health* (ICF).<sup>11 12</sup> In the ICF, functioning and disability are conceptualised as the complex interplay between bodily functions (and the immediate impairment effects of these), activities (and activity limitations), participation (and participation restrictions) and environmental factors. Environmental factors (such as social attitudes and practices, services systems and policies) are explicitly recognised as having a crucial effect on a person’s functioning and social participation (or social inclusion).

This emphasis on the important role played by social structures and socio-cultural practices in defining disability and in shaping the life experiences of people with disabilities results in a clear focus on issues of disability discrimination and ‘disablism’. Discrimination on the basis of disability refers to ‘... any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including denial of reasonable accommodation.’ (CRPD Article 2). Disablism refers to ‘the social beliefs and actions that oppress/exclude/disadvantage people with impairments’ and includes consideration of the overt and systemic (or institutional) discrimination faced by people with certain health conditions or impairments.<sup>3</sup>

This emphasis on the role played by social structures and socio-cultural practices in shaping the life experiences of people with disabilities also draws attention to variations in the living conditions and experiences of people with disabilities across time and cultures.<sup>13</sup> For example, over the past century people with disabilities have variously been thought of as (among other things) innocents close to God, social menaces, objects of pity, non-human and (more recently in some contexts) as oppressed citizens.<sup>14-16</sup> Social responses to people with disabilities in Europe over the

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Macedonia (FYROM), Montenegro, Portugal, Republic of Moldova, Romania, San Marino, Serbia, Slovakia, Slovenia, Spain, Sweden, Turkey, Turkmenistan, Ukraine, United Kingdom

last century have ranged from industrial scale attempts to exterminate people with disabilities in Nazi Germany,<sup>17-20</sup> the widespread institutionalisation and warehousing of children with disabilities,<sup>21</sup> through to the growing voice of the independent living movement, disabled people's organisations and, finally, to the widespread ratification across Europe of the UN Convention on the Rights of Persons with Disabilities.

While it would be comforting to think of these changes in terms of the unrelenting progress of liberal ideals, it is probably more realistic to assume that the breadth of values and social attitudes towards people with disabilities that are reflected in these historical responses remain deeply embedded in contemporary European cultures.<sup>22</sup>



## The Prevalence of Disability

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It has recently been estimated that 15-19% of the world's population are disabled.<sup>1</sup> However, estimates of the prevalence of disability will vary widely as a function of at least three factors:<sup>1 23-26</sup>

- variation in the incidence and prevalence of health conditions and impairments associated with disability;
- variation in the social structures and socio-cultural practices related to disablement;
- variation in the methods used to measure disability and in the quality and comparability of population statistics.

### Variation in the Incidence and Prevalence of Health Conditions and Impairments Associated With Disability

Most is known about the first of these factors. There is extensive evidence from around the world to suggest that risk of many health conditions and impairments associated with disability (and activity limitations associated with these health conditions and impairments) increases with (increasing) age and (reduced) socio-economic position.<sup>27-64</sup>

The following figures illustrate these relationships using data extracted from the World Health Surveys using an operational definition of disability developed by the WHO to inform the WHO/World Bank World Report on Disability.

#### **Box 1: The World Health Survey**

The World Health Survey involved a face-to-face household survey undertaken in 2002–2004. It is the largest multinational health and disability survey ever undertaken using a single set of questions and consistent methods to collect comparable health data across countries. The survey covered the health of individuals in various domains, health system responsiveness, household expenditures, and living conditions. The World Health Survey collected data in 70 countries including 29 of the 53 Member States of the European Region of the WHO. Sampling strategies varied between countries. Sample sizes ranged from 585 in Slovenia to 11,220 in Turkey. In most countries sample sizes were approximately 1,000. Full technical details of the method used to define disability are presented in Technical Appendix C of the *World Report on Disability*.<sup>1</sup> Country reports are available at <http://www.who.int/healthinfo/survey/whsresults/en/index3.html>

Using these data across the 29 countries gave an overall prevalence of disability of 12%. The median within country prevalence of disability rose from 4% among adults aged 18-39, through 12% among adults aged 40-59 to 25% among adults aged 60 or

more. The overall prevalence of disability was significantly greater in poorer countries (association with per capita GDP corrected for local purchasing power, Spearman's  $r=-0.73$ ,  $p<0.001$ ) and in countries with greater levels of income inequality (association with GINI coefficient, Spearman's  $r=-0.42$ ,  $p<0.05$ ). These associations were not statistically significant for prevalence of disability in the 18-39 age group, but were for the 40-59 age group (per capita GDP corrected for local purchasing power, Spearman's  $r=-0.53$ ,  $p<0.01$ ; GINI coefficient, Spearman's  $r=-0.45$ ,  $p<0.05$ ) and the 60+ age group (per capita GDP corrected for local purchasing power, Spearman's  $r=-0.94$ ,  $p<0.001$ ; GINI coefficient, Spearman's  $r=-0.43$ ,  $p<0.05$ ).

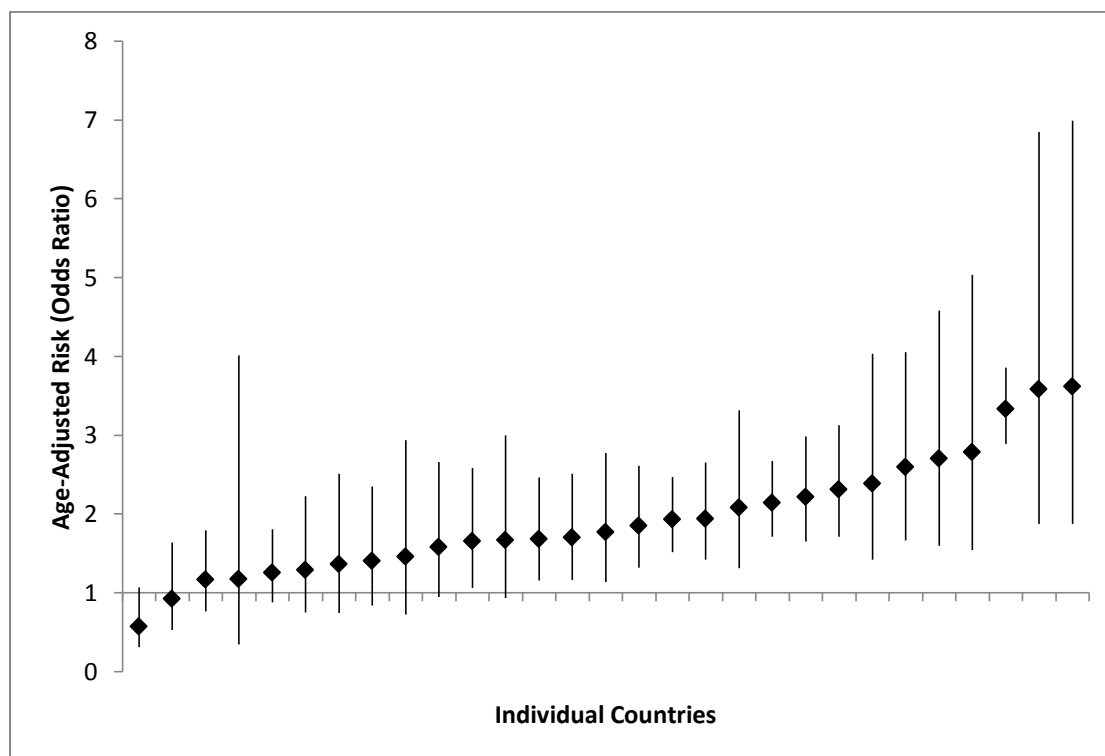
### **Box 2: Making International Comparisons: A Note of Caution**

Making between-country comparisons of the extent of relative disadvantage experienced by disabled people is problematic for four main reasons.

1. Even when using the most rigorous methods, it is difficult to ensure that the essential meaning of questions about health and functioning remains constant when translated into different languages.
2. Peoples' responses to survey questions will reflect their personal expectations (often set in the context of particular reference groups) as well as their actual experiences. These expectations will, of course, vary considerably from country to country. They will also reflect cultural differences in such diverse areas as the use of numerical rating scales (e.g., tendencies to use mid-points or extreme values) and differences in self-presentation (e.g., the social appropriateness of claiming that your health is good or that you have difficulties in functioning).<sup>65</sup>
3. Measures of the *relative* disadvantage of disabled people within a country (including the measures we have used; see Box 3 for details) reflect not only the experiences of disabled people, but also the experiences of non-disabled people. For example, a doubling of the relative risk for an adverse outcome for disabled people (e.g., being the victim of violent crime) is evident in both of the following scenarios: (a) 4% of disabled people have been the victims of crime in the last year compared with 2% of non-disabled people; (b) 100% of disabled people have been the victims of crime in the last year compared with 50% of non-disabled people. The more common a risk is among non-disabled people the more constrained are the upper limits of *relative* risk.
4. The within country sample sizes are relatively small for disaggregating data by disability and outcome. As such, they are likely to contain a reasonable degree of random error.

As a result of these difficulties, we have not named individual countries in the following figures. Our primary concern is to determine whether patterns of within-country disadvantage are replicated across countries, rather than to make comparisons between countries.

Figure 1 presents information on the age-adjusted risk of disability for women (compared with men) in participating countries.



**Figure 1: Age-Adjusted Risk (Odds Ratio) of Disability among Women in 29 European Countries**

The median within country age-adjusted prevalence of disability among women was 12%, among men 7%. In 27 of the 29 countries, prevalence rates for disability were higher among women; in 18 of these countries the difference was statistically significant. In no country was the prevalence rate for disability significantly higher among men.

The overall prevalence of disability was significantly greater in poorer countries for both women (association with per capita GDP corrected for local purchasing power, Spearman's  $r=-0.68$ ,  $p<0.001$ ) and men (association with per capita GDP corrected for local purchasing power, Spearman's  $r=-0.64$ ,  $p<0.001$ ). It was also greater in countries with greater levels of income inequality for both women (association with GINI coefficient, Spearman's  $r=-0.45$ ,  $p<0.05$ ) and men (association with GINI coefficient, Spearman's  $r=-0.32$ ,  $p<0.1$ ), although only the former reached conventional levels of statistical significance.

### **Box 3: Interpreting the Figures**

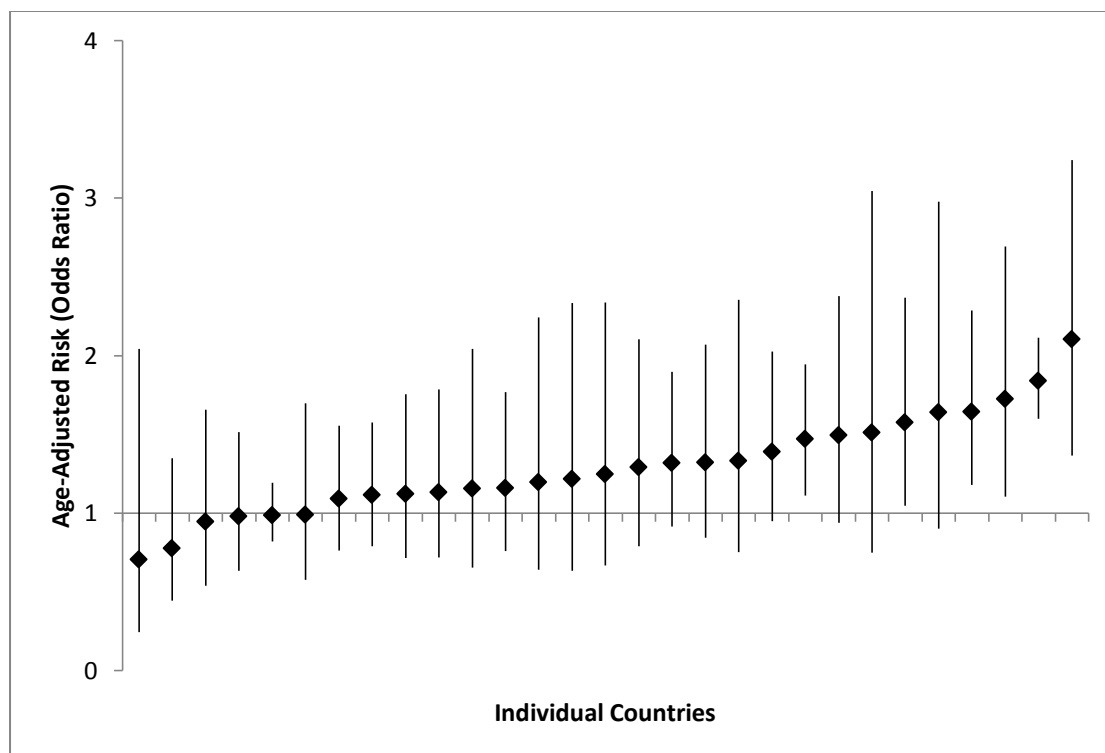
In all subsequent figures we present information for each country on the risk that disabled people, when compared with their non-disabled peers, will experience poorer outcomes. The measure of risk we have used is the odds ratio. The odds ratio is the ratio of the odds of an event occurring for one group (disabled people) to the odds of it occurring in another group (non-disabled people). For example, if the odds of being a victim of crime were 1 in 50 for disabled people and 1 in 100 for non-disabled people; the odds ratio would be 2 (i.e., double the odds for disabled people when compared to non-disabled people).

All comparisons take account (correct for) any differences in age between the two groups. If the diamond marker lies above the line it indicates that disabled people will experience poorer outcomes or conditions. If it is below the line it indicates that disabled people will experience better outcomes or conditions. The vertical lines around the marker show the 95% confidence limits for our estimate of risk. That is, once we take account of possible sampling error, we are 95% confident that the 'true' risk lies within these limits. If the vertical lines do not cross the axis (at 1) we can say that the difference in risk is statistically significant (at  $p < 0.05$ ). The length of the vertical lines primarily reflects the sample sizes in each country. With larger samples we can be more confident of our estimates (and they therefore have shorter lines).

Figures 2 and 3 present information on the association between disability and two indicators of socio-economic position; household wealth and educational attainment. Figure 2 shows the age-adjusted risk that a disabled respondent (compared to a non-disabled respondent) was living in a household in the bottom third of the wealth distribution of that country (wealth being estimated from per capita household expenditure<sup>c</sup>).

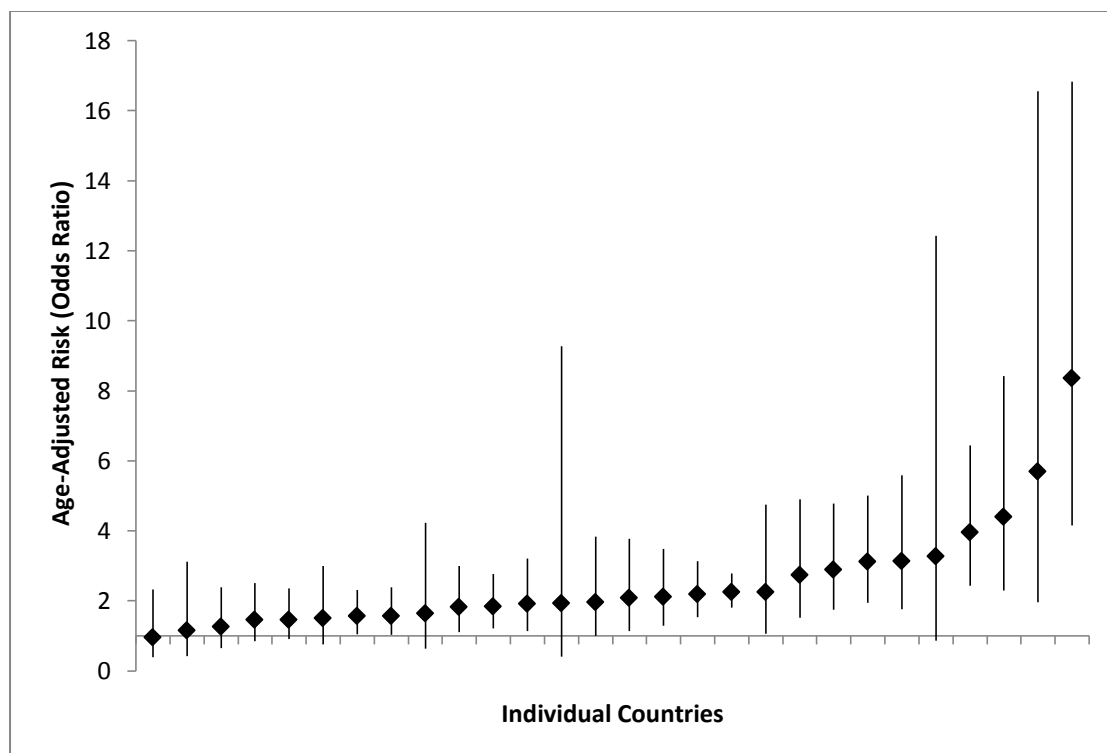
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<sup>c</sup> *Household Expenditure*: The WHS asks respondents a number of questions regarding monthly expenditures. Equivalent per-capita expenditures are calculated by dividing reported total household expenditures by the square root of household size. Households are sorted by per-capita expenditure and grouped into the bottom-, mid-, and top- third for comparisons. For Hungary and Turkey, food expenditures are used due to missing data on total expenditures. Belgium and Spain were omitted due to a high percentage of missing expenditure data.



**Figure 2: Age-Adjusted Risk (Odds Ratio) of Disabled Adults Living in Poorer Households in 29 European Countries**

In 23 of the 29 countries disabled people were at greater risk (when compared to their age-equivalent peers) of living in poorer households. In six countries these differences were statistically significant. In 11 of the 29 countries disabled people were at least 33% more likely than non-disabled people to be living in poorer households. In no country was the risk of living in poorer households significantly higher among non-disabled people. In no country were disabled people at least 33% less likely than non-disabled people to be living in poorer households.



**Figure 3: Age-Adjusted Risk (Odds Ratio) of Disabled Adults Not Having Completed Secondary Education in 28 European Countries**

The median within country age-adjusted Secondary (high) school completion rate was 49% among disabled adults compared with 57% among non-disabled adults. In 27 of the 28 countries for whom data were available adults who were disabled at time of WHS were less likely to have completed high school than non-disabled adults. The probability of this imbalance occurring by chance alone is extremely remote. In 19 countries the within-country difference was statistically significant. For disabled people, there was a trend for school completion rates to be lower in poorer countries (association with per capita GDP corrected for local purchasing power;  $r=0.32$ ,  $p<0.1$ ). There were no other significant association between either national wealth or income inequality and school completion rates.

As noted in Box 2, comparisons *between* countries need to be treated with considerable caution as a result of linguistic and cultural variation in the meaning of translated survey questions. These problems do not, of course, apply to within-country comparisons. What is striking about these data is the consistency of within-country comparisons across a large and remarkably diverse sample of European countries.

In addition, there is some evidence to suggest that people in poorer circumstances may be more stoical in self-reporting limiting health conditions.<sup>66</sup> As a result, the strength of the association between socio-economic position and the prevalence of self-reported disability may be underestimated in these analyses.

## Variation in the Social Structures and Socio-Cultural Practices Related To Disablement

As noted above, disability refers to impairments which in interaction with various barriers in society may hinder full and effective participation in society on an equal basis with others (CRPD Article 1). As a result, we would expect the prevalence of disability to vary as a function of socio-cultural practices and social policies that served to either increase or decrease the risk of the social exclusion of people with particular health conditions and/or impairments. For example, investment in physically accessible public and private transportation and building would be expected to decrease the prevalence and severity of disability among people with mobility impairments. In contrast, cultural beliefs about the ease and mode of transmission of HIV/AIDS can have a profound impact on the degree of stigmatisation (and consequently social exclusion) experienced by people affected. However, disability and health statistics rarely address the measurement of these social barriers to participation in a manner that enables their impact on disability prevalence rates to be estimated.

## Variation in the Methods Used To Measure Disability and in the Quality and Comparability of Population Statistics

Methods used to define and then measure disability vary widely across (and within) European countries in relation to such factors as:

- the types of health conditions and impairments that are considered to be potentially related to disability;
- how the association between any present health conditions or impairments and limitations in activity or restrictions in social participation is measured;
- the measurement of social barriers to limitations in activity or restrictions in social participation;
- the source of the informant (e.g., self-report vs. 'expert' opinion);
- the sampling frame used;
- the specific wording and the sequence of the questions asked;
- the threshold used to define disability.

All of these factors can have an impact on the estimated prevalence of disability and key characteristics of people identified as disabled.<sup>1 23-25</sup>

Difficulties in deriving accurate estimates of the prevalence of disability are exacerbated in Central and Eastern Europe for three reasons.

First, in some countries estimates of the base population size may be unreliable due to undocumented major population movements within and between countries. In Bulgaria, for example, extensive emigration has contributed to a rapid decrease of its

population by 15% from 8.99 million at the end of 1988 to 7.64 million at the end of 2007.<sup>67</sup> Similarly, it is estimated that up to 1 million people have emigrated from Armenia since its independence from the Soviet Union in 1991.<sup>68</sup> Without precise population estimates, there is no reliable denominator to calculate comparable prevalence rates for disability.

Second, a deterioration of official health statistics has occurred in many CEE countries during the transition. Introduction of fees for registration of births and deaths has compromised the completeness of vital statistics in some countries in the Caucasus and Central Asia. For example, birth registration fees amounted to 53% of the average monthly wages in Tajikistan and 10% in Georgia, preventing poor families from registering their children. In Tajikistan, a study conducted by UNICEF in 2000 found that only 75% of children under 5 years of age had been included in the civil registers.<sup>69</sup>

Third, due to definitional differences, reporting is not always comparable to international standards. For example, the Soviet definition of live birth differed from the WHO definition, leading to underestimates of infant mortality by 20-25% in some former Soviet bloc countries.<sup>70-72</sup> In addition, there is evidence of differences in diagnostic procedures and treatment practices in the areas of adults mental health,<sup>73-74</sup> and neurological disorders in children.<sup>75-77</sup>

Interpretation of statistics on numbers of children and adults with disabilities in CEE is difficult because of different definitions of disability depending on the medical conditions and existing limitation in function, changing regulations for entitlement to disability benefits (which entails obtaining official disability status), lack of national registers of disabled people, and lack of reliable and regular medical and social assessments of children and adults living in institutions.<sup>78</sup>

## Summary

Our analyses of WHS data suggest that the overall and median within country prevalence of disability among adults across these 29 European countries was 12%, rising from 4% among adults aged 18-39, through 12% among adults aged 40-59 to 25% among adults aged 60 or more. The prevalence of disability was higher among women than men in 27 of these 29 countries.

Increased rates of disability were also associated with:

- poorer national wealth
- increased within-country income inequality
- female gender
- lower within-country socio-economic position.



# Health Inequalities & People with Disabilities

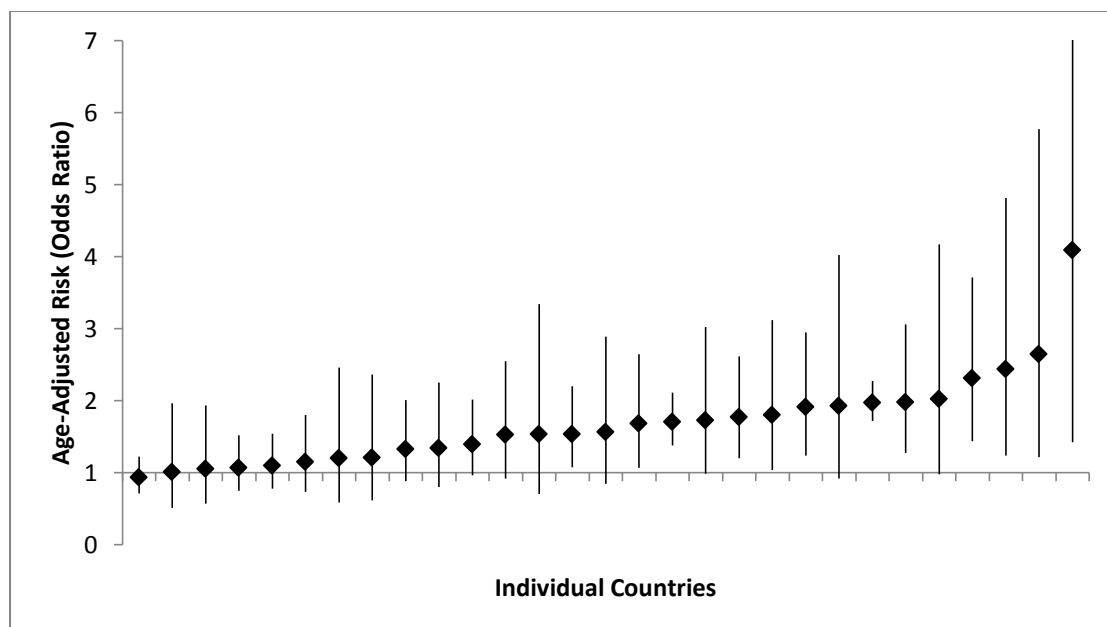
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## Differences in Health Status

There is extensive evidence that people with disabilities experience significantly poorer health outcomes than their non-disabled peers.<sup>79-102</sup> Given that people with disabilities *by definition* must have a health condition or impairment, a degree of difference in overall health status is inevitable. However, these negative outcomes extend to aspects of health that have no known biological link to the *specific* health condition or impairment associated with the person's disability.<sup>82-107</sup> Poorer health outcomes, are also experienced by family carers of children and adults with disability.<sup>108-120</sup>

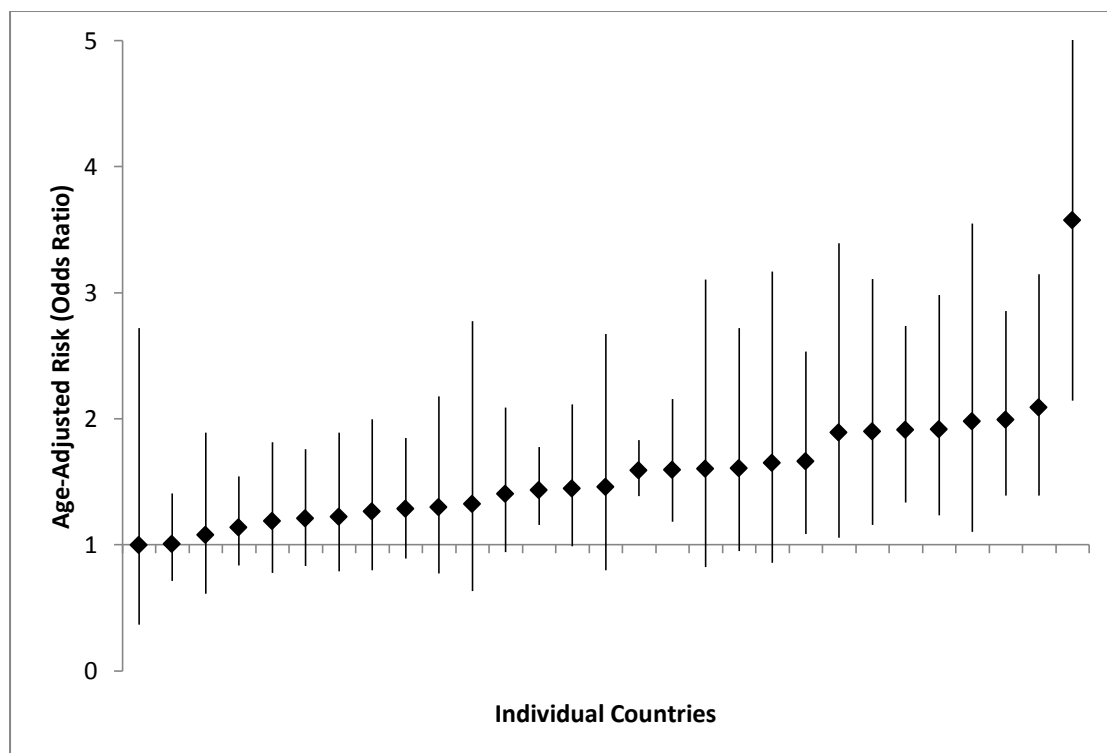
The vast majority of this evidence has been generated in high income countries. Few studies have been undertaken in Central and Eastern Europe. However, numerous reports and qualitative investigations have highlighted the disadvantaged social position of disabled people in Central and Eastern Europe; conditions which would be expected to be associated with poorer quality of life, health outcomes and life expectancy. For example, in a survey in Bulgaria among 1,350 adult citizens in January 2002, 48% of respondents stated that children with disabilities did not receive the special care which would guarantee them a dignified life, independence and active participation in society.<sup>78 121</sup> The respondents identified the following problems faced by disabled children: health problems (55%), isolation from society (49%), not having enough knowledge and skills for an independent life (24%), lack of security (23%) and negative societal attitudes (19%).<sup>78 121</sup>

Figures 4 and 5 illustrate the relationships between disability and health across 29 European countries using data on two indicators of health status (obesity and oral health) extracted from the World Health Surveys 2002-2004. As previously mentioned, the operational definition of disability used was developed by the WHO for the WHO/World Bank *World Report on Disability*. These two indicators were selected on the basis of the availability of data within the World Health Surveys and either the significance of the health condition to population health (obesity)<sup>122</sup> or the low probability that the health condition was itself primarily associated with the identification of disability in the survey (oral health).



**Figure 4: Age-Adjusted Risk (Odds Ratio) of Obesity among Disabled Adults in 29 European Countries**

The median within-country age-adjusted rate of obesity was 21% for disabled adults compared to 14% among non-disabled adults. In 28 of the 29 countries age-adjusted rates of obesity were higher for disabled adults than non-disabled adults. The probability of this imbalance occurring by chance alone is extremely remote. In 12 countries this difference was statistically significant. In no country were rates of obesity significantly higher among non-disabled adults. There was no statistically significant association between either country wealth or income inequality and rates of obesity among either disabled or non-disabled adults.



**Figure 5: Age-Adjusted Risk (Odds Ratio) of Oral Health Problems among Disabled Adults in 29 European Countries**

The median within-country age-adjusted rate of oral health problems was 50% for disabled adults compared to 33% among non-disabled adults. In 28 of the 29 countries age-adjusted rates of oral health problems was higher for disabled adults than non-disabled adults. The probability of this imbalance occurring by chance alone is extremely remote. In 12 countries this difference was statistically significant. In no country was the rate of oral health problems significantly higher among non-disabled adults. Oral health problems were significantly more prevalent in poorer countries for both disabled (association with per capita GDP corrected for local purchasing power, Spearman's  $r=-0.49$ ,  $p<0.01$ ) and non-disabled adults (association with per capita GDP corrected for local purchasing power, Spearman's  $r=-0.77$ ,  $p<0.001$ ). There were no associations between level of income inequality within countries and the prevalence rates of oral health problems for either disabled or non-disabled adults.

## The Social Determinants of Health Inequalities Experienced by People with Disabilities

Four general factors are relevant to understanding the poorer health experienced by people with disabilities in Europe, each of which is amenable to intervention:

- Some health conditions or impairments associated with disability involve increased risk of 'secondary' health conditions or impairments;
- Exposure to well established 'social determinants' of (poorer) health independently increases the risk of health conditions or impairments associated with disability and poor health;
- Disability discrimination increases the risk of exposure to well established 'social determinants' of (poorer) health;
- Disability discrimination reduces access to timely and effective health care.

### *'Secondary' Health Conditions or Impairments*

A number of the health conditions or impairments associated with disabilities appear to be inherently associated with additional health risks. In certain instances these appear to be biologically linked to the health conditions or impairments associated with disabilities. To give some examples:

- people with Down's syndrome (the most common genetic cause of learning disabilities) are more likely to experience congenital heart disease, impaired hearing and early onset dementia;<sup>123-125</sup>
- people with obesity are more likely to experience a range of additional health conditions including cardiovascular diseases, various types of cancer, type 2 diabetes and insulin resistance, end-stage kidney disease, fatty liver disease, osteoarthritis, pulmonary embolism and deep vein thrombosis;<sup>122</sup>
- people who use wheelchairs are at increased risk of pressure sores and urinary tract infection;
- people with Spina Bifida are at increased risk of urinary and bowel incontinence, urinary tract infections and Hydrocephalus.

In other instances, however, the link is clearly mediated by social processes. For example, deaf sign language users are often overrepresented in mental institutions where misdiagnosis and inaccurate interpretation of behaviour is relatively commonplace due to lack of accessible specialist services and deaf mental health professionals.<sup>126-128</sup> Deaf children may be marginalised within their family (unless they are born to deaf parents) and hearing peer groups; they are often linguistically patronised by parents and are at a greater risk from bullying and child abuse.<sup>127</sup> Impairment in either cognition or communication are likely to reduce a person's independent capacity to understand health promotion advice, recognise symptoms

of ill health and negotiate their way through health care systems. To the extent that the link between ‘primary’ and ‘secondary’ health conditions or impairments is mediated by social processes, issues of discrimination come to the fore. The above example could equally be phrased in terms of the failure of health care systems to provide health promotion information and advice in a manner that is accessible to all and to provide alternative means for detecting and treating ill health for people whom it is known will have difficulty using traditional health care systems. We will return to these issues later.

*‘Selection’: Health Conditions or Impairments Associated with Disability and Health Status are Independently Influenced by Common Social Determinants of Health*

As we have seen the incidence and prevalence of many of the health conditions and impairments associated with disability are socially patterned; the higher a person’s position in the social hierarchy, the lower the risk of acquiring health conditions and impairments associated with disability. The same is, of course, true of health in general.<sup>129-136</sup>

As a result, we would expect people with disabilities to have poorer health than their peers simply as a result of a process of ‘selection’. That is, they are more likely to have been exposed to social conditions that *independently* lead to both the onset of health conditions and impairments associated with disability *and* to poorer health in general. For example, exposure to social and material deprivation in early childhood is known to be associated with (among other things) increased risk of intellectual disability<sup>30 123 125</sup> *and* to increased mortality and morbidity in later life.<sup>137-139</sup> As a result, we would expect people with intellectual disabilities to have poorer health than their peers simply because as children they are more likely to have been exposed to conditions that are damaging to future health. This would be expected *regardless* of any effects that having an intellectual disability may have on health (the latter effects will be addressed in the following section).

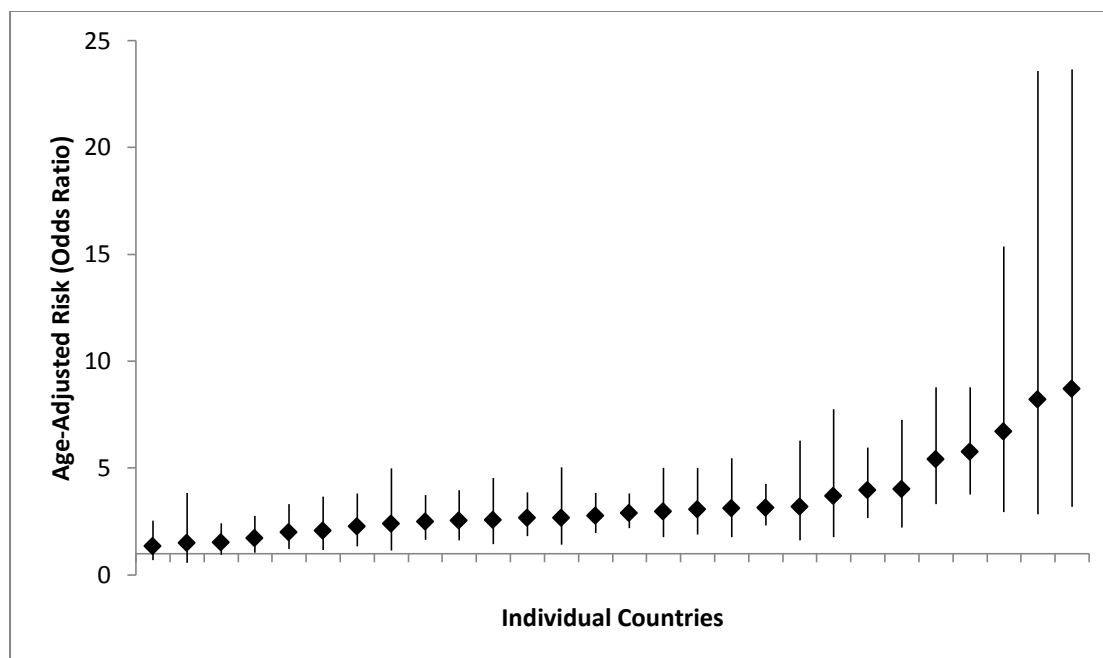
Few studies have attempted to estimate the extent to which the poorer health outcomes experienced by people with disabilities may be attributable to their increased risk of exposure to socio-economic disadvantage (rather than ‘disability specific’ factors). However, the results of this nascent literature suggest that increased risk of exposure to socio-economic disadvantage may account for: 20-50% of the risk of poorer mental and physical health among children with general intellectual impairments;<sup>85-87 140</sup> and most or all of the risk of poorer mental health and low rates of well-being among mothers of children with disabilities or general intellectual impairments.<sup>141-143</sup>

### *Disability Discrimination Increases the Risk of Exposure to 'Social Determinants' of (Poorer) Health*

Disability discrimination increases the risk of poor health through two inter-related processes. First, discrimination may lead to downward social mobility consequently increasing the risk of exposure to common social determinants of health associated with lower socio-economic position. The direct and indirect costs associated with disability may increase the risk of disabled people (and households supporting disabled children) falling into poverty and decrease the chances of them escaping from poverty.<sup>144-150</sup> There is also abundant evidence that disabled people are significantly disadvantaged with regard to key factors that promote upward social mobility including education, employment and labour market experiences, social and cultural capital, health and well-being.<sup>126 151-153</sup>

- *Education* has been identified as one of the most important factors influencing social mobility.<sup>151-153</sup> Disabled children have more unauthorised school absences, are more likely to be bullied and to have poorer academic attainment than their peers (see Table 4).<sup>154-158</sup> Disabled children are also at risk of placement in segregated special schools, including residential special schools, settings that may significantly impede children's social inclusion.<sup>21 159</sup><sup>160</sup> About 90% of the children in special schools in Bulgaria are labelled as having "minor mental disabilities".<sup>161</sup> In Bulgaria, many children are placed in special schools for social reasons. These schools provide social assistance in the form of food, clothes, accommodation and textbooks which serves as an incentive for poor parents to enrol their children.<sup>161</sup> In Bulgaria, as in other countries of Central and Eastern Europe, Roma children are overrepresented in special schools for children with intellectual and physical disabilities. Different estimates indicate that 35% to 50% of those attending special schools for children with learning disabilities were Roma, while the Roma children among the general population are about 10%.<sup>161 162</sup> Lack of standardised diagnostic procedures and over-diagnosis of mental disability among Roma children makes the reliability of the official statistics on disability questionable.<sup>163</sup> The quality of education in special schools is often considered inadequate and may serve to increase inequalities in life opportunities and consequently health, rather than narrow the gap. Many deaf children are deprived of the opportunity to learn and use sign language, develop their cultural identity and have the opportunity to interact with deaf teachers. Consequently, many deaf children have a much poorer chance of achieving their full health potential, a reflection of the widely recognized strong association which exists between inequalities in health status and social inequities.<sup>126 164 165</sup>

- Employment and labour market experiences.* Disabled adults have significantly reduced employment opportunities.<sup>61 156 157 166-185</sup> Figure 6 illustrates the increased risk of non-employment among disabled adults in 28 European countries in 2002-2004. The median within-country age-adjusted non employment rate was 60% for disabled adults compared to 47% among non-disabled adults. In all 28 countries age-adjusted non employment rates were higher for non-disabled adults than disabled adults. The magnitude of the increase in the risk of not being employed ranged from a low of 33% in Austria to over 800% in Bosnia and Herzegovina. The probability of this imbalance occurring by chance alone is extremely remote. In 25 of the 28 countries this difference was statistically significant. In no country were employment rates significantly higher among disabled adults. There was no statistically significant association between either country wealth or income inequality and employment rates of either disabled or non-disabled adults. In some European countries (e.g., Belgium, Italy, Spain) people with disabilities who are employed are most likely to be employed in 'sheltered' settings.<sup>172</sup> When in work, these same groups are more likely to be in low-paid, poor quality jobs with few opportunities for advancement, often working in conditions that are harmful to health.<sup>130</sup> The onset of disability among people in employment is associated with increased risk of subsequent unemployment and reduced earnings.<sup>186-188</sup> Recent reports from nine CEE countries described extremely limited access to employment for people with intellectual disabilities.<sup>189</sup> Stigma and lack of knowledge about mental illness among employers, employees and social workers result in limited opportunities of employment for people with a history of mental health illness.<sup>190</sup> For example, in 2003 in Sverdlovsk Oblast in Russia, 4,600 people with disabilities applied at the employment services, but only 2,000 gained employment. The successful applicants had exclusively physical disabilities, and none of those with mental health problems or intellectual disability was able to find employment.<sup>190</sup>



**Figure 6: Age-Adjusted Risk (Odds Ratio) of Not Being Employed among Disabled Adults in 28 European Countries**

- *Social and cultural capital.* Socioeconomically more advantaged families tend to have access to a wider range of social networks and cultural capital that facilitate upward mobility and protect against downward mobility. Disabled people, as well as experiencing socio-economic disadvantage, also tend to have more restricted social capital as a result of prejudicial and discriminatory practices.<sup>4 157 170</sup>
- *Health and wellbeing.* Ill health can lead to a decline in socio-economic status. As noted above, there is extensive evidence that people with disabilities experience significantly poorer health outcomes than their non-disabled peers, including in aspects of health that are unrelated to their *specific* health conditions or impairments.

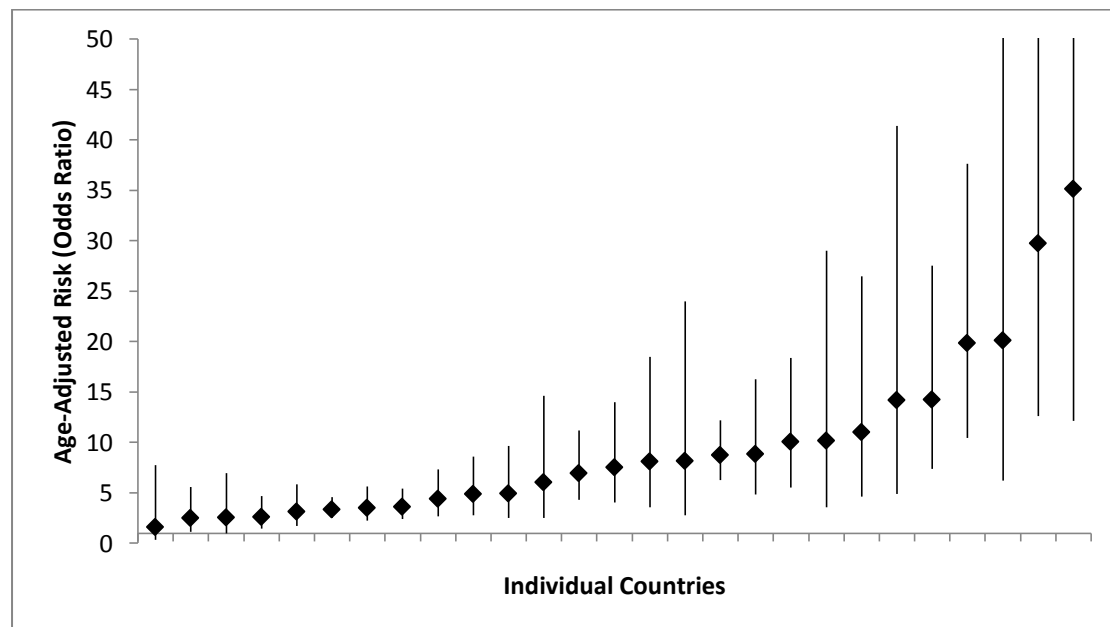
Disability is also associated with reduced social mobility of family carers. Childhood disability is associated with delayed entry of mothers into the workforce and increased rates of parental separation, factors that are likely to impede the social mobility of the families supporting disabled children.<sup>150 191-198</sup> Caring for a disabled adult has been linked to reduced employment opportunities and reduced income.<sup>115 152 199 200</sup>

Second, exposure to overt acts of discrimination in everyday life is likely to have a negative impact on health status. A parallel may be drawn here with the research investigating the determinants of the health inequalities experienced by people from minority ethnic groups. Here, a growing body of research has highlighted the association between exposure to overt acts of racism and poorer health outcomes.<sup>201-208</sup> Exposure to overt acts of disability discrimination is a relatively



common experience for many people with disabilities,<sup>157 170 209-212</sup> and may plausibly be related to poorer health outcomes.<sup>213</sup>

The impact of discrimination (when combined with increased risk of exposure to low socio-economic position in childhood for other reasons [see above]) is likely to significantly disempower people with disabilities. This is illustrated in Figure 7 with data from the World Health Survey.



**Figure 7: Age-Adjusted Risk (Odds Ratio) of Not Being Able to Control Important Things in One's Life among Disabled Adults in 27 European Countries**

The median within-country age-adjusted rate with which people reported being 'fairly often' or 'very often' unable to control important things in their life was 20% for disabled adults compared to just 3% among non-disabled adults. In all 27 countries these age-adjusted rates were higher for disabled adults than non-disabled adults. The probability of this imbalance occurring by chance alone is extremely remote. The magnitude of the increase in the risk of being disempowered ranged from a low of 60% in Slovakia to over 1000% in Belgium, Portugal, Finland, Germany, The Netherlands, Sweden, the Czech Republic and Denmark. In 25 of the 27 countries this difference was statistically significant. There were no statistically significant associations between either country wealth or income inequality and rates of disempowerment among disabled adults. For non-disabled adults, increasing rates of disempowerment were evident in poorer countries (association with per capita GDP corrected for local purchasing power, Spearman's  $r=0.41$ ,  $p<0.05$ ) and in countries with greater rates of income inequality (association with GINI coefficient, Spearman's  $r=0.50$ ,  $p<0.01$ ).

These differences are of particular concern given both the magnitude of the differences and evidence that reported control (or disempowerment) may be an important psychosocial pathway through which the impact of environmental

adversity on health is mediated.<sup>214</sup> These data suggest that 45% of all disempowered adults in these European countries are also disabled.

### *Disability & Institutionalisation*

Historically, institutional 'care' was a central component of social responses to disability in many European countries. In many countries more inclusive community-based alternatives have started to replace institutional provision, but in most countries reliance on institutional 'care' remains strong.

In Central and Eastern Europe, for example, the numbers of children living in institutional care at the end of the 1990s were higher than in 1989.<sup>69</sup> This trend continued during 2000-2006, with Kazakhstan, Lithuania, Moldova and the Russian Federation having the highest rates between 1,313 and 1,670 per 100,000 children aged 0-17 years.<sup>215</sup> There has been increasing rates of infants entering institutional care in Bulgaria, Romania, Estonia, Latvia and other countries of the Former Soviet Union.<sup>216</sup> This is of particular concern as research has shown impairment of brain development among infants raised in institutions, with the first six months being the most crucial period. A survey of 32 European countries in 2003 estimated that 23,099 children under the age of 3 in institutions representing an average rate of 11.2 per 10,000 children under 3 years of age.<sup>217</sup> Several countries had at least three times higher than the average rates, including Bulgaria, the Czech Republic, Hungary, Latvia, Lithuania and Romania, with the highest rate found in the Czech Republic at 60 per 10,000.<sup>217</sup> In the EU (2003) countries surveyed 4% of children were placed in institutions because of disability, while in other surveyed country 23% were placed because of disability. This is indicative of underdeveloped services to support families with disabled children in the community in Central and Eastern Europe, which has been reported elsewhere.<sup>218</sup>

Severe violations of human rights have been documented in several of these institutions.<sup>218 219</sup> It has been reported that in Romania, Bulgaria and other CEE countries the children's institutions had a strong medical orientation, provided little intellectual or social development activities and the care revolved around basic medical needs.<sup>78 220</sup> Research shows that serious deficiencies in care provision for young children placed in institutions often lead to developmental delay and cognitive, social, behavioural and emotional disorders.<sup>221</sup> In institutions children fail to attach securely to significant adults, which leads to difficulties in the areas of social competence, and peer and sibling interactions.<sup>217</sup> Prospective studies of Romanian children adopted in the UK have found that the length of time spent in institutional settings was the primary predictor of the prevalence and persistence of behaviour and developmental problems.<sup>222</sup> The majority of institutionalised children with moderate or severe intellectual disabilities are transferred to institutions for adults, once they reached adulthood.<sup>223</sup>

People living in institutions are cut off from society and rarely receive visitors. Often children's institutions discourage links with parents or extended family.<sup>224</sup> The lack of services for disabled people in the community means that disabled children and adults are excluded from participation in society and deprived of social networks.<sup>189</sup>

Funding for institutions for disabled people is often insufficient for meeting the physical needs of their residents of nutritious food, warmth and clothing as well as for structural repair and maintenance. A report from Amnesty International from 2002 described the condition in institutions for mentally disabled people in Bulgaria as "worse than imprisonment".<sup>225</sup> During the winter of 1996/1997, 13 children died from malnutrition and hypothermia in a home for children with mental disabilities near Plovdiv in Bulgaria. The court proceedings concluded that neglect on the part of the state had left the home without financial means for providing food and heating.<sup>78</sup> A survey conducted in 1993/1994 among 615 children under the age of 3 years in Mother and Child Homes, showed that 41.7% had weight below the normal range, and 26.5% had height below the normal range.<sup>226</sup>

Observations in institutions for disabled children and adults have established lack of essential forms of rehabilitation and therapy.<sup>227</sup> People with severe disabilities may be left all day confined in their beds, without any stimulation or organized activities.<sup>228</sup> Lack of adequate treatment and rehabilitation for children in institutions impairs their development and the possibility of leading a more meaningful life. According to an assessment by Amnesty International, many of the residents of adult social care institutions would have been able to lead an independent life, had they been adequately rehabilitated and trained in the institutions for children where they had previously resided.<sup>219</sup> In many cases lack of expertise to diagnose and treat children with disabilities is one reason for their placement in institutions. Lack of social rehabilitation services in the community may lead physicians to encourage parents to surrender children with physical and mental disabilities to institutions.<sup>229</sup> The destiny of children born with a disability is often decided by the health staff in the maternity unit, without provision of adequate counselling and support to the parents.<sup>230</sup> According to a study in Bulgaria among 60 mothers of children with intellectual disability, the majority of parents (73.3%) were dissatisfied with the way they were informed about the child's diagnosis, without sufficient information about the condition itself (80%), and without further referral to appropriate specialists (48.3%).<sup>231</sup>

The negative effects of institutionalization are summarized in Box 4.

**Box 4: The Effects of Institutionalisation (Adapted from<sup>232</sup>)**

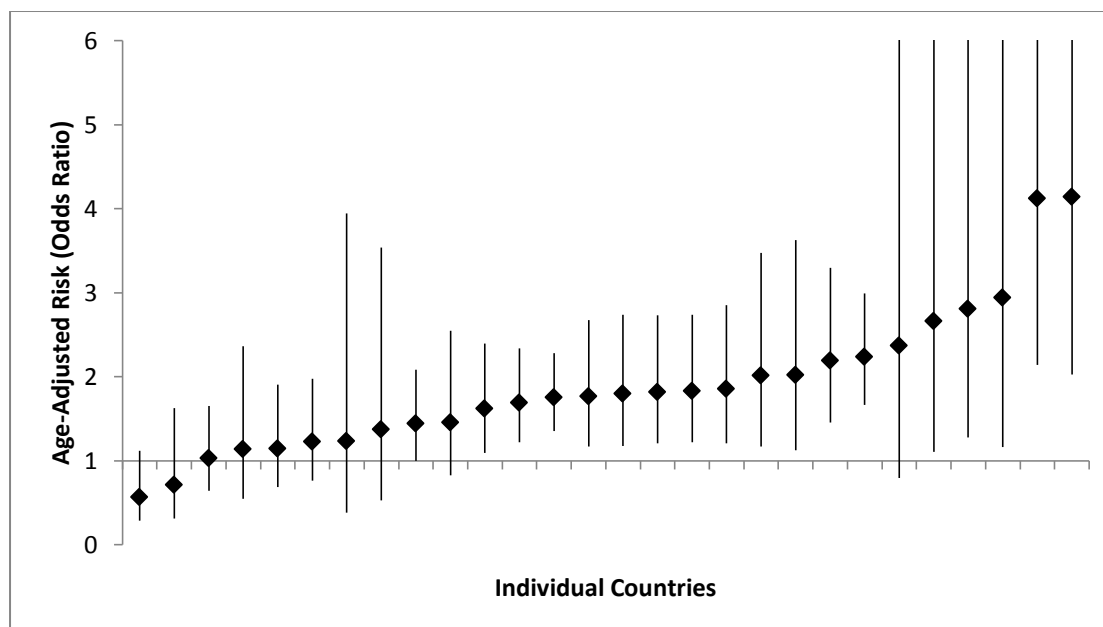
- Impaired early brain development, delayed physical and cognitive development, in some cases resulting in intellectual disability
- Children in institutions are more likely to have low educational attainment and poor employment prospects
- Raised anxiety, sleeping disorders, eating disorders, enuresis
- Attachment disorders, low self-confidence, self-harming, non-compliance and aggressive behaviour
- Institutions leave children ill-prepared to live in the outside world
- Institutions often discourage contact with family and deprive young people from social networks

It is important to focus on people with disabilities living in special institutions because their rights are often violated. In this report it is also important, because they are often excluded from surveys on public health and health status etc. Institutionalised populations (as well as children) were for example excluded from the World Health Survey data, which the World Disability Report and the tables in this publication are based on (World Report on Disability, p. 293).

*Disability Discrimination Reduces Access to Health Information and Timely and Effective Health Care*

Finally, discrimination in health care systems is evident in the range of organisational barriers that have been identified that prevent people with disabilities in accessing timely and effective healthcare.<sup>80 81 126 233-254</sup> These include: scarcity of services; physical and financial barriers to access; inadequate transportation; failure to make 'reasonable adjustments' in light of the literacy and communication difficulties experienced by people with cognitive or sensory impairments; and discriminatory attitudes among healthcare staff. Barriers are evident in relation to health screening and health prevention and promotion,<sup>170 236 237 255-263</sup> primary health care<sup>264-266</sup> and secondary health care<sup>267-272</sup> as well as rehabilitation services. Discrimination also includes stereotyping and stigmatizing, which can lead to denial of health care services even when they are notionally available and accessible.

The experience of discrimination in health care is likely to be reflected in both utilisation of health care services, worse health outcomes and in lower overall satisfaction with health care among persons with disabilities. The latter is illustrated in Figure 8 with regard to having a low level of satisfaction with health care.



**Figure 8: Age-Adjusted Risk (Odds Ratio) of Being 'Fairly' or 'Very' Dissatisfied with the Way Healthcare is Run among Disabled Adults in 28 European Countries**

The median within-country age-adjusted rate with which people reported being 'fairly' or 'very' dissatisfied with the way healthcare is run was 29% for disabled adults compared to 17% among non-disabled adults. In 26 of 28 countries these age-adjusted rates were higher for disabled adults than non-disabled adults. The probability of this imbalance occurring by chance alone is remote. In 18 countries this difference was statistically significant. In no country was dissatisfaction significantly higher among non-disabled adults. Increasing rates of dissatisfaction were evident in poorer countries for both disabled (association with per capita GDP corrected for local purchasing power, Spearman's  $r=0.54$ ,  $p<0.01$ ) and non-disabled adults (association with GINI coefficient, Spearman's  $r=0.59$ ,  $p<0.01$ ). There were no statistically significant associations between income inequality and rates of satisfaction/dissatisfaction.

Care for mental health illness in Central and Eastern Europe, particularly in many countries of the former Soviet Union, is provided almost exclusively by psychiatric specialists in inpatient facilities, concentrated mainly in the large cities. In Russia 63% of psychiatric hospitals have more than 500 beds and 19% have more than 1000.<sup>273</sup>  
<sup>274</sup> There is also a tradition of weak collaboration between primary care and mental health services. Community mental health services are underdeveloped, so that patients with mental disorders who would be treated in the community in the West are frequently admitted to hospitals. A study on pathways to psychiatric care in Central and Eastern Europe found that more than half of new patients contacted directly the psychiatric services, circumventing primary health care.<sup>275</sup> General practitioners (GPs) were found to have a limited role and often provided no treatment to mentally ill patients presenting in primary care. The study found that

GPs rarely prescribed antidepressants, and more commonly sedatives or hypnotics which were perceived as carrying less stigma.<sup>275</sup> Research on mental health services in the Russian Federation found a prevailing therapeutic pessimism about the possibility of recovery from enduring mental illness and deeply engrained beliefs in the necessity of long-term institutionalization of patients.<sup>276</sup> The management of mental illness focuses predominantly on the medical aspects of treatment, without adequate attention to social rehabilitation and integration.<sup>190</sup>

## Summary

In this section we have described and quantified the extent of health inequalities faced by people with disabilities in Europe and summarised what is known about some of the determinants of these health inequalities. We have drawn attention to four general factors, each of which is amenable to intervention:

- Some health conditions or impairments associated with disability involve increased risk of 'secondary' health conditions or impairments;
- Exposure to well established 'social determinants' of (poorer) health independently increases the risk of health conditions or impairments associated with disability and poor health;
- Disability discrimination increases the risk of exposure to well established 'social determinants' of (poorer) health;
- Disability discrimination reduces access to health information as well as timely and effective health care.

## Policy Options

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There already exist a plethora of policies across European countries that seek to reduce health inequalities. As we have seen above, increased risk of exposure to common social determinants of health is one of *the* key drivers of the health inequalities faced by people with disabilities. As such, policies that successfully reduce exposure to these determinants *should* also reduce the health inequalities faced by people with disabilities. Our recommendations are designed to build on these existing initiatives, by making them more sensitive to the situation of disabled people, and link these to existing international disability policy developments.

**Our overall and first recommendation is for all the countries in the European region to ratify and implement the CRPD.** Ratification and implementation of CRPD will be significantly supported by country commitments to the implementation of related declarations such as the European Parliament Resolutions on Sign Languages for the Deaf and the European Declaration on the Health of Children with Intellectual Disability.

As stated in the recent WHO/World Bank World Report on Disability:

*The ultimate goal of the Report and of the CRPD is to enable all people with disabilities to enjoy the choices and life opportunities currently available to only a minority by minimizing the adverse impacts of impairment and eliminating discrimination and prejudice.<sup>1</sup>*

While ratification of the CRPD will not automatically bring benefits to disabled people, it may help to provide a focus for political action with regard to the implementation of specific policies that lead to the progressive realisation of the rights of disabled people.

There is also a clear need within public health communities to increase the levels of awareness of and understanding of disability in relation to general efforts to reduce health inequality.<sup>277</sup> All too often the discussion of strategies to reduce health inequalities policies pays little or no attention to the situation of people with disabilities (or other marginalised groups). For example, the interim statement of the World Health Organization (WHO) Commission on the Social Determinants of Health did not mention disability *at all* in any of its 53 pages.<sup>278</sup>

Perhaps it is assumed that the benefits of population-level interventions or interventions targeted at deprived areas or families will accrue equally across all social groups? There is considerable evidence, however, that behaviour change interventions (whether ‘upstream’ or ‘downstream’) aimed at reducing health inequalities are likely to be more effective if they are tailored to the specific social and cultural contexts experienced by ‘high risk’ groups.<sup>279</sup> Without such attention to

the specific situation of people with disabilities, there is a real risk that they may fail to benefit from the ‘trickle down’ effects of ‘generic’ social policies.<sup>280</sup> Indeed, as has recently been pointed out in relation to reducing health inequalities:

*‘For specific groups who face particular disadvantage and exclusion, additional efforts and investments and diversified provisions will be needed to reach them and to try to reduce the multiple disadvantages they experience.’<sup>130</sup>*

Similarly, the Rio Political Declaration on Social Determinants of Health (which the UK signed on 21 October 2011) calls for states to ‘develop policies that are inclusive and take account of the needs of the entire population *with specific attention to vulnerable groups*’ [emphasis added]. While ‘vulnerable groups’ clearly includes people living in poverty, it also includes disabled people.

Therefore as an important ‘process recommendation’ for the Review itself we **recommend that the Review should establish an Equality Impact Assessment Panel to consider for each recommendation made in the final report:**

- **The likely impact of the recommendation on marginalised or disadvantaged groups (including people with disabilities);**
- **What specific modifications or adjustments need to be made to ensure that marginalised or disadvantaged groups (including people with disabilities) experience equal benefits from the proposed initiative.**

Furthermore, we **recommend that the Equality Impact Assessment Panel includes, as a full member of the Panel, a representative of Disabled People’s Organisations across Europe.**

Given the marked variation in the situation of people with disabilities across the 53 Member States of the WHO Europe Region, our recommendations will of necessity often be of a general nature.

We **recommend that each country adopts an action plan for gradually reducing inequality in health faced by people with disabilities.** This is in line with recommendation 3 of the 2011 WHO/World Bank *World Report on Disability* and would mean that all states are to produce an action plan **in cooperation with national DPOs** (including DPOs representing people with the full range of chronic health conditions associated with disability) with the aim to reduce inequalities in health for people with disabilities by 50% in 10 years and totally in 20 years. A progress report should be presented every year to the parliament and civil society.



The action plan should be based on the CRPD and should as a minimum clearly describe

1. who is responsible for the different steps/measures in the plan
2. when the steps shall be taken
3. which are the costs and
4. how cooperation with civil society is secured
5. how shall the follow process be performed

A summary of the action plan should draw attention to the steps being taken in each country to address the three overarching recommendations of the WHO's Commission on the Social Determinants of Health:

- *Improve daily living conditions* (of people with disabilities) by, for example, reducing stigma and prejudice (CRPD Article 8; World Report recommendation 7), ensuring that all disabled people have an adequate standard of living and access to education, employment and all relevant public services, especially health services (CRPD Article 9, 16, 19-30; World Report recommendation 1). This will, *of necessity*, require the replacement of all institutional forms of residential and day service provision for people with disabilities with inclusive community-based alternatives (CRPD Article 19);
- *Tackle the inequitable distribution of power, money, and resources* by, for example, addressing the widespread discrimination and disadvantage faced by many people with disabilities across Europe (CRPD Articles 1, 4, 5, 12-16; World Report recommendation 1) and by ensuring that Disabled People's Organisations are centrally involved in key national and international developments (World Report recommendation 4);
- *Measure and understand the problem and assess the impact of action* by, for example, improving data collection at national and international levels to ensure that the health inequalities faced by disabled people (and the determinants of these inequalities), including people living in institutional settings, can be routinely captured in health and social statistics and by increasing investment in disability research (CRPD Article 31; World Report recommendations 8 and 9).

It would also be relevant to initiate a European mechanism for collecting and communicating the action plans and various national initiatives aimed at reducing health inequalities for people with disabilities in Europe. A European mechanism for following up on the action plans would both increase the commitment among the member states and facilitate learning.

Finally, we **recommend that the European Regional Office of WHO convene a meeting in 2013 or 2014 to review progress and share experience on reducing health inequalities faced by disabled people across the region.**

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