

Evidence for gender responsive actions to prevent and manage **chronic conditions**

Young people's health as a whole-of-society response



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Keywords

GENDER IDENTITY

SEX FACTORS

ADOLESCENT

CHRONIC DISEASES

DISABLED PERSONS

HIV INFECTIONS

Abstract

The WHO Regional Office for Europe supports Member States in improving adolescent health by recommending comprehensive, multisectoral and evidence-informed adolescent health approaches; by delineating the critical contribution of the health sector; by fostering actions towards reducing inequalities; and by addressing gender as a key determinant of adolescent health. This publication aims to support this work in the framework of the *European strategy for child and adolescent health and development*, and is part of the WHO Regional Office for Europe contribution to the development of a new policy framework for Europe, *Health 2020*, for which the WHO Regional Office for Europe has been mandated by the 53 Member States.

The publication summarizes current knowledge on what works in preventing and managing chronic conditions. It is part of a series that includes social and emotional well-

being, chronic conditions and disabilities, adolescent pregnancy, HIV/STIs, overweight and obesity, violence, injuries and substance abuse.

The publication assumes the position that young people's health is the responsibility of the whole society, and that interventions need to be gender responsive in order to be successful. It therefore looks at actions at various levels, such as cross-sector policies, families and communities actions, and interventions by health systems and health services. The publication does not prescribe nor recommend any particular course of action, which needs to be informed by the country specific context. It rather provides a basis to stimulate countries to further refine national policies so that they contribute effectively to the health and well-being of young people.

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health and development http://www.euro.who.int/__data/assets/pdf_file/0011/81848/Action_Tool.pdf.

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Foreword

In May 2011, the World Health Assembly adopted a resolution urging Member States to accelerate the development of policies and plans to address the main determinants of young people's health.

This series of publications, advocating a whole-of-society response to young people's health, and looking at the evidence for gender responsive actions, will be a timely resource for Member States as they implement both the resolution and the European strategy for child and adolescent health and development. The publications clearly show that not only are the health, education, social protection and employment sectors jointly responsible for the health of adolescents, but that effective interventions do exist. Ensuring that adolescents who are pregnant or have children can stay in or return to school, or enacting regulations to limit unhealthy snacks and soft drinks in school cafeterias are examples of policies that are beyond the mandate of health systems and yet generate health. By bringing evidence to the attention of policy-makers, these publications take a practical step toward achieving one of the core aims of the new European policy for health, Health 2020: to promote and strengthen innovative ways of working across sector and agency boundaries for health and well-being.

A common shortcoming of adolescent health programmes across the WHO European Region is that they often look at adolescents as a homogeneous cohort. Far too often programmes are blind to the fact that boys and girls differ in their exposure and vulnerability to health risks and conditions, such as depressive disorders, injuries, substance abuse, eating disorders, sexually transmitted infections, violence and self-inflicted injuries, including suicide. They are affected differently not only by the socioeconomic circumstances of their community and their ethnicity but also by gender norms and values. Research shows this, yet there is insufficient progress in transforming knowledge into policy action. I hope this publication will be a useful tool to facilitate this transformation.

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Introduction

The WHO Regional Office for Europe supports Member States in improving adolescent health in four main ways: by recommending comprehensive, multisectoral and evidence-informed adolescent health approaches; by delineating and supporting the critical contribution of the health sector, including the leadership role of ministries of health to influence other sectors, such as education, employment and social protection policies; by fostering actions towards reducing inequities in health both within and between countries; and by addressing gender as a key determinant of adolescent health.

By bringing together and coherently interconnecting knowledge and evidence on effective interventions and good practices for the better health, equity and well-being of young people, this publication aims to support this work using the framework of the *European strategy for child and adolescent health and development*. It is also part of the WHO Regional Office for Europe's contribution to the development of a new policy framework for Europe, *Health 2020*, for which the WHO Regional Office for Europe has been mandated by the 53 Member States (resolution EUR/RC60/R5).

The publication summarizes current knowledge on what works in preventing and managing chronic conditions. It is part of a series that includes social and emotional well-being, chronic conditions and disabilities, adolescent pregnancy, HIV/STIs, mental health, overweight and obesity, violence, and injuries and substance abuse.

The publication includes two parts. The first part is a summary table of effective interventions and good practices in preventing and managing chronic conditions. The table emphasizes intersectoral governance and accountability for young people's health and development, and takes a whole-of-society approach to young people's health. It therefore looks at actions at various levels, such as cross-sector policies, families and communities actions, and interventions by health systems and health services.

It demonstrates that health systems in general, and health ministries in particular, can work proactively with other sectors to identify practical policy options that maximize the positive health effects of other policies on young people's well-being, and minimize any negative effects. Interventions need to be gender responsive in order to be successful; the publication therefore looks at presented practices through a distinct gender perspective.

The second part explains the impact of gender norms, values and discrimination on the health of adolescents relevant to the prevention and management of chronic conditions. Through a review of the existing evidence, it looks at why is it important to look at gender as a determinant of adolescence health, what are the main differences between girls and boys in exposure to risk, norms and values and access to services, and what are the different responses from the health sector and the community. It complements the Gender Tool of the European strategy for child and adolescent health and development http://www.euro.who.int/__data/assets/pdf_file/0020/76511/EuroStrat_Gender_tool.pdf. It gives readers a deeper understanding of the gender dimension of actions listed in Part I.

The evidence base of this publication includes a review of existing literature, such as scientific and research articles and books, policy reviews, evaluations, and 'grey' literature. It needs to be emphasized that this is not a comprehensive and systematic review of the evidence in the area of chronic conditions, nor of approaches to support policies and their implementation. The publication does not rank presented interventions and good practices in any priority order, and does not assess them against the strengths of the evidence behind them. The publication does not prescribe nor recommend any particular course of action, which needs to be informed by country specific context. It rather provides a basis to stimulate countries to further refine national policies and strategies so that they contribute effectively to the health and well-being of young people.

Chronic conditions and disability

PRIORITY	CROSS SECTOR ACTIONS		FAMILY & COMMUNITY ACTIONS	HEALTH SYSTEM ACTIONS	HEALTH SERVICES ACTIONS
	HEALTH IN ALL POLICIES	SCHOOL SETTING			
Manage chronic conditions and disability (including management and care for adolescents living with HIV infection)	<p>Enforce effective antidiscrimination legislation [5]</p> <p>Put in place social assistance system which adequately covers the costs of care for families and adolescents suffering from chronic conditions [1-4]</p> <p>Develop specific vocational tracks for adolescents with chronic conditions [1-4, 6]</p>	<p>Ensure a school climate which facilitates the integration of young people with chronic conditions [1-4, 6], including measures to avoid victimization for bullying of adolescent with chronic conditions [21]</p> <p>Improve the school physical environment and foster integration of adolescents with disabilities [7] including sport activities with special attention to differential gender pattern [22]</p>	<p>Support and foster self help & empowerment organizations [1, 4, 9]</p> <p>Develop mentoring programs for parents and families [1, 4]</p> <p>Ensure access to sports and physical activities for disabled adolescents (e.g. those using wheelchairs) or those suffering from cardiac/pulmonary illnesses [8]</p>	<p>Implement youth friendly health services [14]</p> <p>Train professionals to meet the needs of adolescents with chronic conditions [15]</p> <p>Develop home care and day care as an alternative option to hospitalization [1, 12, 13]</p> <p>Train professionals in the supervision of therapeutic adherence [16]</p> <p>Promote evidence base to elucidate the relationship between chronic health conditions and health care needs among adolescent boys and girls [24, 25]</p> <p>Implement confidential free HIV testing [10, 11]</p>	<p>Ensure coordinated transition from paediatric to the adult health care setting [17]</p> <p>Improve the coverage with primary care services based on needs, including psychological support [7, 18, 19]</p> <p>Effectively manage chronic pain [20]</p> <p>Increase opportunities of psychological support for adolescents suffering from chronic pain [18]</p> <p>Implement specific multidisciplinary care for adolescents with HIV [10, 11], including coordinated multidisciplinary transitional care services and long term follow up for young adults with perinatally acquired HIV-1 infection [23]</p>

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Gender impacts on adolescent health with focus on chronic conditions, including HIV infection

“In order to ensure that women and men of all ages have equal access to opportunities for achieving their full health potential and health equity, the health sector needs to recognize that they differ in terms of both sex and gender. Because of social (gender) and biological (sex) differences, women and men face different health risks, experience different responses from health systems, and their health-seeking behaviour, and health outcomes differ.”

Source: Strategy for integrating gender analysis and actions into the work of WHO. Geneva, World Health Organization, 2009.

Why should chronic conditions policies and interventions pay attention to gender?

Although some might argue that gender inequalities in health are a natural consequence of biological differences and therefore difficult to change, gender inequality and inequity in health are socially governed and therefore actionable (Sen and Ostlin, 2010). Recognizing the root causes of

differences between adolescent girls and boys in regard to exposure and vulnerability to health risks as well as identifying potential mental health protective factors is therefore crucial when designing responses from the health and other sectors in order to be effective (Ostlin et al., 2006).

Chronic conditions and disabilities, including HIV infection among adolescent girls and boys – what do we know?

Globally, one in ten adolescents suffers from a chronic condition (Suris, 2003). Although the prevalence of chronic conditions among adolescents is difficult to assess due to the lack of quality data focusing specifically on this age group, as well as the diversity in methodology and definitions used, surveys carried out by self administered questionnaires among in-school adolescent populations indicate that around 10% of adolescents suffer from such a condition (Suris, Michaud and Viner, 2004).

There is paucity of international comparative data, and only one study aiming at analysing United Nations data on young people (ages 10–19 years) with disabilities was identified. The purposes of the study were: highlighting available information on these populations by age and gender; (b) analysing interrelationships among and between disability prevalence rates for young people and socioeconomic, health, and geographic variables; and (c) recommending future research. Utilizing the United Nations

International Disability Statistics Database (DISTAT), 19 countries with reported data on 10- to 14-year-old young people and 23 countries with data on 15- to 19-year-old young people with disabilities were analysed. Independent variables included geographic location, age, sex, gross national product (GNP), female illiteracy, access to health care, infant mortality, life expectancy and fertility rate. There was a wide variance in disability rates for young people among the countries studied. Consistently, adolescent males had higher rates than females. A positive correlation was found between disability rates and GNP, and consistently higher rates were noted for rural areas. There appears to be a lack of consistency in definitions of disabilities among countries studied, which influences prevalence rates. Finally the study suggested that higher rates for males may reflect gender bias in the provision of medical interventions in many developing countries (Suris and Blum, 1993).

A study conducted in Germany aiming at estimating the prevalence and characteristics of children and youth with special health care needs (CSHCN) showed that the overall weighted prevalence of CSHCN was 16.0% among boys and 11.4% among girls. Up to 14 years, the sex difference persisted through all age groups. Children with a migrant background had significantly lower rates of CSHCN compared to non-migrants. This was particularly true for boys (8.0% vs. 17.1%). CSHCN status was not related to social status, urbanization or residence in former West vs. former East Germany. Except for the lack of association with social status, these results are in accordance with observations from the US National Survey of CSHCN (Scheidt-Nave et al., 2007).

The same authors studied the association between chronic health conditions and specific health care needs among children and adolescents in Germany. A chronic health condition was defined based on standardized parent questionnaires and computer-assisted parent interviews regarding any lasting illness or health problem, congenital malformation or officially recognized disability. As part of the parent questionnaire, the validated German version

of the Children with Special Health Care Needs (CSHCN) screener was used to assess special health care needs. Overall, 38.7% of the study population had at least one chronic health condition, as compared to 73.0% of children and adolescents who were identified as having specific health care needs. Only 25.8% of children and adolescents with chronic health conditions were found to have any special health care needs. However, this proportion varied considerably according to the type of health condition. Overall 3.7% of study participants screened positively for special health care needs, while no specific chronic health condition was reported by their parents. In multiple logistic regression analyses, factors independently associated with the absence of perceived health care needs among children and adolescents with chronic health conditions included female gender, migration background, a lower socioeconomic status, residence in former West Germany, a lower number of concomitant health problems, and the absence of behavioural problems. The identification of special health care needs among children and adolescents without any reported chronic health condition was determined by male gender, having no migration background, and evidence of behavioural problems. Further analyses are necessary to elucidate the relationship between chronic health conditions and health care needs among children and adolescents. These need to focus on specific health conditions and should include additional information on health-related quality of life, health care services use, and psychosocial resources (Scheidt-Nave et al., 2008).

Some studies have shown gender differences in the prevalence of wheezing and asthma. Boys are consistently reported to have more prevalent wheezing and asthma than girls. In adolescence, the pattern changes and the onset of wheezing is more prevalent in females than males. Asthma, after childhood, is more severe in females than in males, and is under-diagnosed and undertreated in female adolescents. Possible explanations for this change is the gender susceptibility to develop asthma including hormonal changes and gender-specific differences in environmental exposures (Almqvist, Worm and Leynaert, 2008).

Health risk behaviours among adolescents with chronic conditions

A growing body of literature indicates that adolescents with chronic conditions are as likely, or more likely, to take risky behaviours than their healthy peers. A study conducted in Switzerland aiming at assessing sexual behaviours, sexual orientation, pregnancy, and abuse history among adolescents with and without chronic conditions, showed that adolescents with chronic conditions are at least as sexually involved as their peers, and significantly more likely to have been sexually abused. Visibility of chronic conditions does not appear to affect the sexual behaviours of adolescents. The need for comprehensive sexuality education in this population is high, and discussion of sexuality, contraception and abuse must be part of standard psychosocial assessment and anticipatory guidance for all teenagers, including those with chronic conditions (Suris et al., 1996).

Using data from a French national health survey carried out among 7,936 adolescents (mean age = 16.2 years), research aiming at comparing sexual behaviour in adolescents with a physical handicap or a chronic illness to a healthy group showed the following results: 52% of boys and 38% of girls with chronic conditions reported sexual intercourse (vs. 42% of boys and 28% of girls). Girls with chronic conditions or physical handicap reported more often changing partners, pregnancy, and use of oral contraceptives. On the other hand, boys with chronic conditions or physical handicap reported more often receiving information on sexuality from their parents (Choquet, Du Pasquier and Manfredi, 1997).

In Catalonia, Spain a study conducted with the aim of assessing whether adolescents with chronic illness differ from their healthy peers in risk-taking behaviour, showed the following results: the prevalence of chronic conditions was 9.6%, with females showing a higher prevalence than males. The intervention groups showed similar or higher rates of sexual intercourse and risky sexual behaviour. For most studied drugs, boys with chronic conditions reported slightly lower rates of use, while girls with chronic conditions showed higher rates for every drug studied. No dif-

ferences were found in the perceptions of drug use among peers or in their school. Hence, chronically ill adolescents are as likely, or more likely, to take risky behaviours than their healthy counterparts and should receive the same anticipatory guidance (Suris and Parera, 2005).

Chronic conditions seem to be also a risk factor for victimization from bullying. A study conducted among 7005 students (48% females) aged 16-20 years, distributed into adolescents with chronic conditions (728, 50% females) and controls (6277, 48% females) showed that the prevalence of bullying was 13.85%. Adolescents with chronic conditions were more likely to be victims of bullying, and to be victims of two or three forms of bullying. Victims of bullying with chronic conditions were more likely than non-victims to be depressed, to have more physical symptoms, to have a poorer relationship with their parents, to have a poorer school climate, and to have been victims of sexual abuse or other forms of violence. Although these characteristics apply to victims in general, in most cases they are less pronounced among victims without chronic conditions (Pittet et al., 2010).

The prevalence of obesity is growing worldwide, especially in the population of adolescents with intellectual disabilities. A study conducted in France, showed that 30.2% of participants were overweight, including 9.5% exhibiting obesity, with girls significantly more concerned by pre-obesity than boys; individuals with Down's syndrome were significantly more obese than those without genetic disorders; individuals taking psychotropic medications were significantly more obese than those who did not; no difference in prevalence could be identified regarding the level of intellectual disability and the presence or not of pervasive developmental disorders. The prevalence observed in this study is clearly higher than those observed in the general population. This creates a supplementary handicap for the social inclusion of this population, and highlights the need that specialized institutions should become aware of the recent development of this secondary illness (Begarie et al., 2009).

In relation to chronic conditions and protective health

factors, a study conducted in Switzerland showed that having a chronic condition seems to influence sports practice among males but not females. Males with chronic conditions were less likely than control males to practice sports, whereas no significant difference was observed for females. Chronically ill youth were significantly more likely to report having a chronic condition as a barrier for not practicing sports. However, the most frequently reported barrier was preference for other activities for males with chronic conditions and lack of time for control males and for females with and without chronic conditions. It is therefore recommended that practitioners dealing with adolescents remember to take into account sports practice as part of the care of young patients with chronic conditions (Pittet et al., 2009).

HIV infection

The Russian Federation and the Ukraine are among the eastern European countries with the fastest growing number of cases of HIV. According to data from the Joint United Nations Program on HIV/AIDS, nearly 90% of newly reported HIV diagnoses in eastern Europe in 2006 were from the Russian Federation (66%) and the Ukraine (21%). A growing number of women are infected with HIV. The impact of gender on HIV/AIDS is an important factor in understanding the development and evolution of the HIV/AIDS epidemic in eastern Europe.

A study conducted in both countries using reported HIV/AIDS cases from the official epidemiological register of the Ukrainian Centre for AIDS Prevention and data from the Russian Federal AIDS Center (Joint United Nations Program on HIV/AIDS country fact sheets were also reviewed and analysed) showed that of the newly registered cases of HIV, the proportion of women rose from 13.0% in 1995 to 44.0% in 2006 in the Russian Federation, and from 37.2% in 1995 to 41.9% in 2006 in the Ukraine. There has also been a considerable increase in mother-to-child transmission of HIV since 1995. Between 1987 and 1994, the proportion of children among the people newly infected with HIV in the Ukraine was 2.2%; in 2006 it was 17.6%. In 2006, 16,078

new HIV cases were registered in the Ukraine and 39,652 new HIV cases in the Russian Federation. Large increases in the number of HIV-infected women were reported from both countries (Burruano, Kruglov and Marcyunovskaya, 2007; Burruano and Kruglov, 2009).

Since 1990, the Russian Federation has experienced a dramatic increase in the number of abandoned children, associated with harsh socio-economic conditions, increases in drug and alcohol addiction and HIV infection. Approximately 20% of infants born to HIV-positive mothers are abandoned in the Russian Federation. To find out why, a qualitative study was conducted of 266 people in 2004-05 in four Russian cities, including HIV-positive women who had abandoned their infants and others who had not, relatives of the women (mostly their mothers), HIV-negative women who had abandoned, and medical experts. Unintended pregnancy was cited as the most important factor influencing the decision to abandon. Other important determinants included lack of a partner and family support, drug abuse, fear of birth defects or disabilities, negative attitudes of medical professionals, and marginalized socio-economic status. HIV infection was closely linked to many of these reasons. Important avenues for interventions among HIV-positive women emerged, including improved contraceptive information and provision, education of medical personnel and women on HIV prevention and treatment, enhancement of social support, and strengthening of fostering and adoption programmes for HIV-affected families (Zabina et al., 2009).

The burden of HIV among MSM in Slovenia is disproportionately high and increasing fast. A study conducted in Slovenia during 1999-2008 showed that among the 48 newly diagnosed HIV cases reported for 2008, 34 were MSM. Since 1999, the annual reported rate of HIV diagnoses in MSM rose from 7.1 to 46.8 per million men aged 15-64 years (an increase of more than six times). During 1999-2008, the proportion of MSM diagnosed with AIDS within three months of HIV diagnosis declined from 60% to 21%, however, the corresponding rate per million men aged 15-64 increased from 4.3 to 9.6. During 1999-2008, HIV preva-

lence among male clients of STI outpatient services tested for syphilis (including a substantial proportion of MSM) increased from 0% to 3.4%, and it remained below 5% in a sentinel population of MSM in Ljubljana. In the same population of MSM, the proportion reporting HIV test last year increased from 29% in 2003 to 38% in 2008 while the

proportion reporting condom use at last anal intercourse decreased from 81% in 2004 to 66% in 2008. The promotion of safer sexual behaviour and HIV testing among MSM as well as positive preventions among MSM with diagnosed HIV infection are urgently needed (Klavs et al., 2009).

What are the explanations behind the differences in chronic conditions and disabilities among adolescent girls and boys?

Understanding the way in which biological sex (e.g. sex hormones) and social factors (e.g. gender norms) interact in different aspects of health related behaviours and health outcomes is central to the understanding of how gender operates in health and health related behaviours (Sen and Ostlin, 2008). Unfortunately there is paucity of studies focused on explaining the mechanisms behind the differences in chronic conditions and disabilities, including HIV infection among adolescent girls and boys, and often these differences, as in the case of HIV infections are time and context specific. Moreover, possible explanations often make reference to a potential combined effect.

In the case of asthma for example, possible explanations for the change around puberty in the gender susceptibility to develop asthma include hormonal changes but also gender-specific differences in environmental exposures (Almqvist, Worm and Leynaert, 2008).

A study conducted in Sweden aiming at establishing gender difference amongst newly diagnosed type 1 diabetic patients aged 15-34 years, showed that the mean annual incidence rate of type 1 diabetes was 12.7/100,000, in men 16.4/100,000 and in women 8.9/100,000. The incidence of type 1 diabetes decreased slowly by increasing age but was in all age groups higher in men, yielding an overall male/female ratio of 1.8. In both sexes the incidence of type 1 diabetes decreased in average of 1.0% per year. A clear male predominance of type 1 diabetes was seen in all ages. Internal factors related to the sex rather than differences in the exposure to environmental factors seem to explain the consistent male-female bias in the post pubertal risk of developing type 1 diabetes (Ostman et al., 2008).

Are policies and programmes managing chronic conditions and disabilities, including HIV infection gender sensitive?

Recognizing gender inequalities is crucial when designing health promotion strategies. Without such a perspective, their effectiveness may be jeopardized, and inequities in health between men and women, boys and girls are likely to increase (Ostlin et al., 2006). However, in many European countries most of the programmes designed to prevent and manage chronic conditions and disabilities, including HIV infections, are not gender sensitive. Gender sensitivity in policies and programmes requires a high quality of studies free of gender bias. Yet some studies tend to assume that sex differences (biological factors) and gender differences (social factors) are the same, thus making it difficult to provide the right guidance for identifying appropriate public health responses. Another problem is the lack of monitoring and evaluation of the already existing programs and intervention studies. This makes it difficult to ensure evidence-based practice and policies or to prevent subjecting boys and girls to interventions which show no benefit or interventions that could unintentionally lead to harm, i.e. what may eventually work for boys with chronic conditions may not always work for girls and may even be counterproductive.

In light of the reviewed literature, we may conclude that little is known about the health care needs among adolescent boys and girls with chronic conditions. Further analyses are necessary to elucidate the relationship between chronic health conditions and health care needs among children and adolescents. These need to focus on specific health conditions and should include additional information on health-related quality of life, health care services use, and

psychosocial resources (Scheidt-Nave et al., 2008).

As chronic conditions seem to be a risk factor for victimization from bullying and as adolescents with chronic conditions are increasingly mainstreamed, schools should be encouraged to undertake preventive measures to avoid victimization of such adolescents.

Children with perinatally acquired HIV-1 infection are surviving into adolescence and increasingly transitioning toward adult services. Young adults with perinatally acquired HIV-1 infection require coordinated multidisciplinary transitional care services and careful long-term follow-up in adult life. Interactions between ethnicity and gender are to be taken into consideration when planning appropriate services (Foster et al., 2009).

The importance of integrating gender consideration into the creation of HIV programs has been documented. To protect women from HIV infection, it is important to find ways to empower them by implementing policies and specific prevention measures that increase their access to knowledge about HIV/AIDS; the empowerment of women is vital to reversing the HIV/AIDS epidemic (Burruano, Kruglov and Marcynovskaya, 2007; Burruano and Kruglov 2009). At the same time, the promotion of safer sexual behaviour and HIV testing among MSM as well as positive prevention among MSM with diagnosed HIV infection are urgently needed (Klavs et al., 2009).

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