

## **Module A4: Confidentiality, consent, rights, and personal advocacy**

### **Entry Scenario**

*The entry scenario addresses a variety of issues and problems associated with the module topic. It may be used at the beginning of the course to stimulate the students to identify their own needs and interests. The results may be utilized by the individual to assess own learning process, or be integrated with class objectives.*

A mother and her 15 year-old son come to see you. The parents are divorced, father has legal custody of the child, and the parents do not communicate with one another. The mother is concerned that her son seems to be constantly tired, lethargic and uninterested in doing anything with friends. The school reports that the boy sometimes falls asleep during classes and that his schoolwork, which has never been outstanding, is showing no signs of improvement. The boy himself says virtually nothing, mumbles inaudible comments when asked direct questions, and refuses to make eye contact. You ask the mother to leave so that you can talk to her son alone. After you make a prolonged effort to gain his confidence by explaining that you are there to help him and that anything he says will remain confidential, the boy finally admits that he goes clubbing every Friday and Saturday night, that he takes an Ecstasy tablet on weekends, and that is about all that he really enjoys in life. He is totally adamant that he does not want his parents to know any of this. The mother returns to your consulting room – how would you handle the situation from that point?

### **General Goals for Learners**

*By completing the module the participant will be able to:*

- I. Understand how the issues raised by the UN Convention on the Rights of the Child relate to one's particular practice with adolescents
- II. Understand and apply the concepts of 'confidentiality' and 'informed consent' to one's practice when dealing with adolescents

**Goal I.**

**Understand how the issues raised by the UN Convention on the Rights of the Child relate to one's particular practice with adolescents**

	<b>Training Objectives</b> Key topics to be covered	<b>Educational Methodology</b>	<b>Activities, Issues, and Questions</b>
<b>KNOWLEDGE</b>	<p><b>A. Know the UN Convention on the Rights of the Child and European Convention on Human Rights.</b></p> <ul style="list-style-type: none"> <li>- Basic premises</li> <li>- Comparison of the above two documents</li> <li>- Country-specific applications and interpretations</li> </ul> <p><b>*Throughout the teaching of other modules participants should be asked to examine how the Convention might affect what they are being taught. For example, how does it apply to module B4?</b></p>	<p>Background reading or handouts of documents</p> <p>supplemented by introductory lecture</p> <p>other pedagogical methods could be used:</p> <p>VIPP</p> <p>Talking sticks</p> <p>(see module D1 training)</p>	<p>Different countries will have different approaches to the Convention on the Rights of the Child. Participants should be asked to find out how the Convention is applied to adolescents in their own countries. If several countries are represented in the audience, a short discussion comparing the methods of applying the document would be informative.</p> <p>Different countries will also have different ideologies concerning individual rights against societies' rights, and these should be shared and discussed (i.e. political and legal issues). If possible, get participants to voice which legal structures in their countries they think may impinge on the rights of the adolescent (Use these ideas in advocacy section, Goal III).</p>

	<b>Training Objectives</b> Key topics to be covered	<b>Educational Methodology</b>	<b>Activities, Issues, and Questions</b>
	<b>B. Consider the implications of young people having rights</b>	Class discussion Case studies  Other pedagogical methods: Fishbowl VIPP document p 110 Pro contra	Discuss why young people need rights. Discuss the implications of the cultural, ethnic, ethical, legal and moral issues as well as how war, poverty, education, exploitation, labor, family demands and expectations, and migration may also impinge on a young person's rights. Guidance should be given that participants understand the complexities inherent in the issues concerned, underlining the importance of treating cases individually. <u>Case study</u> A 15 year-old immigrant Muslim girl from Pakistan attends your clinic asking for contraception. What specific factors would you discuss concerning her rights to this, in light of her cultural and educational background? <u>Case study</u> A 10 year-old girl with a mother with breast cancer asks to be tested to see if she is carrying the gene.
<b>SKILLS</b>	<b>C. Consider how the Convention affects one's practice and how to put it into action</b>	Small group work  Other pedagogical methods: Facilitated discussion Round about	Small groups reflect on questions: 1. In what specific ways do you think that your own medical practice with adolescents will need to be changed in light of the UN Convention on the Rights of the Child? 2. In what specific ways do you think that the Convention might actually <i>impede</i> (legal and practical issues) the way that you deliver your services to adolescents?

Training Objectives Key topics to be covered	Educational Methodology	Activities, Issues, and Questions
<p><b>D. Address the specific requirements of Article 12 of the UN Convention:</b> <i>“States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child.”</i></p>	<p>Handout of UN article 12 Focus groups with involvement of young people</p>	<p>The goal of the focus group is that participants understand why they should seek the opinion of young people, by finding out</p> <ul style="list-style-type: none"> <li>- what <i>young people</i> consider their major health problems,</li> <li>- how easy <i>young people</i> find accessing medical facilities, and</li> <li>- how <i>young people</i> want health related information provided for them.</li> </ul> <p>Questions for participants:</p> <ol style="list-style-type: none"> <li>1. What questions would you specifically want to ask the adolescents in your practices about the services you provide?</li> </ol> <p>How could you best involve young people in answering these questions?</p>

**Goal II.**

**Understand and apply the concepts of ‘confidentiality’ and ‘informed consent’ to one’s practice when dealing with adolescents.**

	<b>Training Objectives</b> Topics to be covered	<b>Educational Methodology</b>	<b>Activities, Issues, and Questions</b>
<b>KNOWLEDGE</b>	<p><b>A. Define ‘confidentiality’ between practitioner and adolescent, and discuss potentially problematic issues</b></p> <ul style="list-style-type: none"> <li>- Basic philosophy</li> <li>- Issues of legal structure, ethics, family issues, culture, patient maturity, medical teamwork</li> </ul>	<p>Background research</p> <p>Group discussion</p>	<p>To the extent possible, participants research the legal structures in their own countries that impact confidentiality for adolescents. In class discussion, participants discuss how circumstantial factors can alter the basic philosophy that “the professional should not disclose anything learned from a person who has consulted them, or whom he or she has examined or treated – without that person’s agreement.” Discussion points should include,</p> <p>The rights of the parents to know, The rights of the child not to have others know, The rights of a school to know about a child who might have an infectious disease such as AIDS. Dilemma question: how should the issues be prioritized?</p>
<b>SKILLS</b>	<p><b>B. Decide on the application of the confidentiality principle for single cases in complex situation.</b></p>	<p>Role play</p>	<p><u>Case study</u>: A 14 year-old girl who asks you to arrange an abortion for her also asks that her parents not be informed. Role-play the situation, with practitioner discussing the issues concerning her cultural background, her age, and her religion with her. Identify what specific outcomes one is seeking to achieve. How will confidentiality be assured? Class develops several more short but complex examples.</p>

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<b>KNOWLEDGE</b>	<p><b>C. Discuss, and place in context, ‘medical consent’ for adolescents</b></p> <ul style="list-style-type: none"> <li>- Working definition</li> <li>- Legal basis</li> <li>- Country-specific regulations</li> <li>- Issues stemming from terms such as ‘informed’, ‘maturity’, and ‘on behalf of’.</li> </ul>	<p>Short lecture by a lawyer knowledgeable in the issues concerning ‘consent’</p> <p>Group discussion</p> <p>Small group work/role play</p>	<p>Lecture addresses such points as what medical consent for young people actually entails, what are the legal issues, who can give it and when (according to the specifics of the host country). How does consent relate to procedures, investigations, or treatments?</p> <p>Class discusses questions that arise in the individual application of the concept of consent for young people such as determination of maturity, the practicalities of ‘informing’, what the true meaning is of ‘informed’ in relation to consent, and how consent can be influenced by the setting.</p> <p><u>Case studies</u></p> <ol style="list-style-type: none"> <li>1. A 14 year-old with leukemia that has relapsed several times wants to cease his treatment. Who can give consent to this and how much does the patient’s opinion have to be taken into account? What is the medical practitioner’s specific role in obtaining consent and why?</li> <li>2. Parents who are Jehovah’s witnesses refuse to allow their daughter who has been in a severe accident to have a blood transfusion. How should you as the child’s medical practitioner approach this? What legal actions will you have to go through to override the parent’s wishes?</li> </ol>

**Goal III.**

**Clarify the role of the health professionals as advocates for adolescent health on a personal and structural level.**

**Common set of slides with module C3 Advocacy**

	<b>Training Objectives</b> Topics to be covered	<b>Educational Methodology</b>	<b>Activities, Issues, and Questions</b>
<b>KNOWLEDGE</b>	<b>A. Determine the rationale for advocacy and how it might apply to different health professionals in different settings</b>	Class discussion	<p>Class discuss the following premises that form a rationale for advocacy:</p> <ol style="list-style-type: none"> <li>1. Young people do not have the right to vote and therefore lack political power.</li> <li>2. Adolescents are inexperienced at promoting their needs in an effective way and may lack the appropriate language.</li> <li>3. A myth exists that adolescents are healthy compared with other age groups, and do not need the same level of services.</li> <li>4. The media is antipathetic and critical of adolescent behaviors.</li> </ol> <p>Get participants to describe an occasion where they have acted as an advocate for an individual adolescent. What are the limits to one's professional 'obligation'?</p>

	<b>Training Objectives</b> Topics to be covered	<b>Educational Methodology</b>	<b>Activities, Issues, and Questions</b>
<b>ATTITUDES</b>	<b>B. Identify personal motivations and concerns which may influence one's ability to act freely as an advocate for adolescents</b>	Small group work/role play	<p>Participants discuss case studies in small groups with the aim of identifying for themselves their personal attitudes about advocacy. Questions to be kept in mind include,</p> <ol style="list-style-type: none"> <li>1. Whose specific interests are you representing?</li> <li>2. Is your advocacy free from financial concerns?</li> <li>3. What is the specific aim of your advocacy?</li> <li>4. Does your advocacy have legal implications?</li> <li>5. How would your status as a parent influence your advocacy in individual cases?</li> </ol> <p><u>Case study:</u> A teenage couple consults you. The girl is 15 and pregnant. The father, aged 17, wants her to keep the child; the girl wants an abortion. Whom are you advocate for? – The mother, the father, the unborn child or for the principles concerned? And what is behind your advocacy?</p>



	<b>Training Objectives</b> Topics to be covered	<b>Educational Methodology</b>	<b>Activities, Issues, and Questions</b>
<b>ATTITUDES &amp; SKILLS</b>	<b>C. Consider the personal implications of advocacy for adolescents on a structural level</b>	Class discussion	<p>In preparation, participants are asked to privately consider the question, “Should you be broadening your advocacy to include a whole client group, such as <b>all</b> young people in your practice with disabilities?” Follow with open class discussion of what conditions must be present for participants to agree to take up a community or national advocacy role in relation to adolescent health. Use case studies to encourage the individual participant’s involvement in discussion.</p> <p><u>Case studies</u></p> <ol style="list-style-type: none"> <li>1. You have been consulted by a boy at your local school who is being bullied for being a homosexual. How do you provide advocacy on his behalf at the school and in the community as a whole? How might you take it up as a national issue?</li> <li>2. The national government proposes to stop providing free contraception to anyone under the age of 18. How do you advocate against this move on behalf of adolescents?</li> </ol> <p>Using participants’ examples from Goal I objective A, discuss becoming involved to change legal structures which impinge on adolescents’ rights</p>



## Resources

- **The European Convention on Human Rights**

<http://www.hri.org/docs/ECHR50.html>

- **UN Convention on the Rights of the Child**

<http://www.unicef.org/crc/crc.htm>

[http://www.unicef.org/crc/index\\_30160.html](http://www.unicef.org/crc/index_30160.html) (accessed July 2016)

- **Policy statement on informed consent, parental permission, and assent in pediatric practice**

<http://aappolicy.aappublications.org/cgi/reprint/pediatrics;95/2/314.pdf> (no access possible)

- **USC Keck School of Medicine (Adolescent Health Curriculum)**

<http://www.usc.edu/adolhealth/> (is it updated regularly? To check)

- **Child and adolescent development (WHO)**

<http://www.who.int/child-adolescent-health/publications/publist.htm> (no access and must be updated with the health of the world's adolescent for example)

- **Larcher V. Consent and confidentiality. In: ABC of adolescence. Ed Viner R. Blackwell Publ 2005**

<http://www.bmj.com/content/330/7487/353.full> .

**Michaud PA, Blum RW, Benaroyo L, Zermatten J, Baltag V.**

Assessing an Adolescent's Capacity for Autonomous Decision-Making in Clinical Care

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[http://www.jahonline.org/article/S1054-139X\(15\)00257-8/references](http://www.jahonline.org/article/S1054-139X(15)00257-8/references)