

PUBERTY AND SEXUALITY

TEACHING PLAN GUIDE



HELSE BERGEN

Haukeland University Hospital

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PUBERTY AND SEXUALITY



Introduction

This teaching plan is aimed at children and adolescents with Asperger syndrome and high-functioning autism, and addresses puberty and sexuality in a visual, concrete, and structured manner. Its purpose is to ensure that pupils are equipped with adequate knowledge in these subject areas, and to stimulate reflection and curiosity in the pupil in the company of an appropriate adult – preferably in collaboration with a public health nurse. The material has also proved suitable for other students requiring a visual and structured teaching approach.

About Us

Marlin Haarstad is a qualified social educator, specialising in clinical milieu therapy. She has also studied pedagogy. Marlin has worked with people with autism since 1995, and draws on broad experience from community living facilities, day care centres, primary and lower secondary education, and support services. For the past 13 years, she has worked as specialist advisor at Helse Bergen's specialist outpatient department, the Autism Team. Her current role involves follow-up, guidance, treatment, training, and professional development. In autumn 2016, she was appointed head of the special educational needs department at Loddefjord skole in the municipality of Bergen.



Annie Mathisen is a qualified child welfare officer, with a background in psychiatry and sexology. She currently works as specialist advisor at Helse Bergen's specialist outpatient department, the Autism Team. Furthermore, she is a co-author of the report: "The establishment of procedures for prevention, notification, and follow-up of abuse against individuals with intellectual disabilities and other vulnerable adults with developmental disorders" (the SUMO project). Annie has extensive experience delivering guidance and training courses for educators, next of kin, and service providers in topics relating to sexuality and relationships.



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We kindly ask that and feedback, requests for alternative topics, and other enquiries are directed to us.

Thank you!

We have had the privilege of working with several excellent contributors in the preparation of this teaching plan. First and foremost, a special thanks to employees in municipalities outside of Bergen who readily have agreed to try something new and untested. We would also like to thank Helse Bergen for approving this project and for allowing us to develop this much-needed material during our working hours.

Thanks to the professional network of psycho-educative groups in Helse Bergen for their input, and for their help with recruiting suitable individuals willing to test this plan together with their pupils. Thanks to RFSU for the material provided.

Thanks to the Regional Resource Center for Autism, ADHD, Tourette's syndrome, and Narcolepsy for NOK 25 000 in project funding.

Thanks to Wenche Fjeld for permission to use her images.

Thanks to the Autism Team's specialist advisors for their review of and feedback on the teaching material.

Thanks to Trym who has made several of the excellent drawings used.

And last, but not least; thanks to trainee social educator, Kristin Bjerland, for her support during the final preparation phase.

Annie and Marlin



Preface

The purpose of the school health services and public health centres is to prevent mental, physical, and social developmental disorders in children and adolescents from 0 to 20 years old. Public health nurses meet with everyone in this age group, and are therefore ideally placed to offer relevant guidance and support to both parents and children. It is important that children and adolescents get to know their own bodies and the changes that are taking place, both physically and mentally, during puberty. Being aware of the natural changes puberty brings, may help pupils feel more confident. Puberty education in primary and lower secondary school is offered for groups as well as at class level.

As a public health nurse, I have not had access to a teaching plan on puberty aimed specifically at pupils with Asperger syndrome or autism. This collaboration project, initiated by Marlin in the Autism Team, is therefore a very positive step forward. The teaching plan is partially based on the material used

by public health nurses for classroom lessons, and has been adapted by Marlin to suit pupils with Asperger syndrome and high-functioning autism.

I have had the opportunity to test the programme on one pupil, and this has worked extremely well. The pupil had already attended classroom lessons on the topic, and had good basic understanding.

It is paramount that we, as public health nurses, offer tailored education to reassure and instil confidence in children and adolescents with Asperger syndrome and high-functioning autism in terms of changes taking place in the body. This is in line with our statutory duty to prevent mental, physical, and social developmental disorders.

I would like to thank Marlin for the valuable and informative collaboration, and I wish her every success with the publication of this teaching plan.

Yours Sincerely Bente Brurås, Public Health Nurse

Key difficulties with Asperger syndrome/high-functioning autism

“The diagnosis is referred to as a pervasive developmental disorder due to its impact on all functional areas that develop from infancy to adulthood. This disability affects all areas of life, and marks all aspects of everyday living. However, the extent of difficulties in various areas differs greatly.” (Martinsen et al. 2007, 15/330.)

Perhaps the simplest way to understand Asperger syndrome and high-functioning autism* (hereinafter referred to AS and HFA), is to think of it as describing someone who perceives and thinks about the world differently to other people (Attwood 2007, 12).

People with AS/HFA are often of high intellectual ability, but are characterised by an uneven skills profile. They may be highly adept in some fields, and display severe problems with understanding in other areas. As their most common problem is dealing with situations that most people cope with naturally, they are often perceived as peculiar and different (Martinsen et al 2007, 15).

Individuals with AS/HFA experience challenges in three core areas:

1. Reciprocal social interaction
2. Reciprocal verbal and non-verbal communication
3. Imagination and behaviour

These impairments will mutually influence one another. Deviations in all of these functional areas are often referred to as Lorna Wing’s Triad (Gillberg 1998, 25). Wing’s Triade can be illustrated as follows:

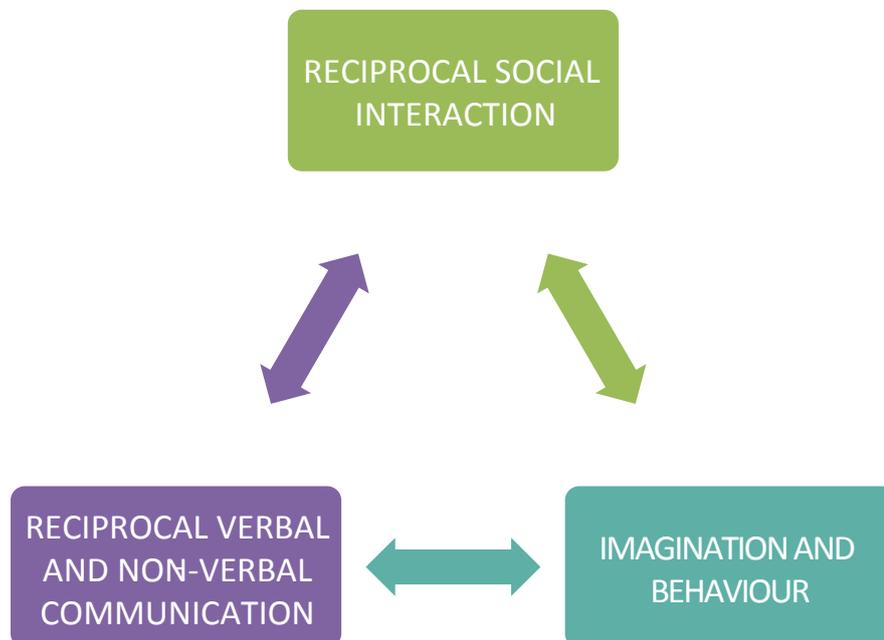


Fig. 1: High-functioning autism is defined as individuals on the autism spectrum with abilities within the average range. Lorna Wing’s Triad of Impairments illustrates the pervasive disorders that mutually influence one another.

Communication and language impairments are extensive, despite the ability to use well-formed sentences and breadth of vocabulary not being affected. Individuals with AS/HFA may struggle to understand that different words can have the same meaning and that identical words can have different meanings. Some also struggle to understand that statements expressed in different tones of voice, intonation patterns and levels of emphasis, may have the same meaning (Martinsen et al. 2007, 17). Individuals with AS/HFA are often preoccupied with the concrete/precise meaning of a word; i.e. a literal/concrete understanding of language (Martinsen et al. 2007, 16). Impaired understanding of non-verbal communication and the emotional expressions of other people, is often combined with impaired ability to identify and describe own emotions (Martinsen et al. 2007, 19).

An example is Henrik – a 15-year-old boy with Asperger syndrome. He was highly articulate, and was able to use advanced vocabulary compared with others his own age. Yet, his understanding of language was very literal, and he found aspects such as irony difficult to comprehend. Furthermore, indirect messages from adults with hints that he was unable to grasp would often confuse him. For example, his teacher sometimes asked “Have you got your book out now?” when he wanted Henrik to put his book on his desk. Henrik would then reply “no”, as was the truth, and he did not pick up on the hint that he should put his book on his desk. This often caused misunderstandings that confused Henrik – an example that many are likely to recognise.

Impaired understanding of social situations and non-verbal communication makes it difficult for individuals with AS/HFA to read other people’s emotions, interests, and intentions. In addition, they have a limited social repertoire and find it difficult regulate contact and interaction (Martinsen et al. 2007, 20). Understanding social rules, norms, and conventions is characterised by the same literal thinking as their understanding of language, and it can be difficult for these individuals to comprehend social interaction and the purpose of rules and conventions (Martinsen et al. 2007, 21). Communicative and social challenges will often become more obvious during secondary school, as peers move on from concrete play.

Lack of interest in other people is linked to *restricted repetitive and stereotyped patterns of behaviour, interests, and activities*, which is the third area where individuals with AS/HFA experience difficulties. Most individuals with AS/HFA have special abilities and interests, referred to as special interests. The difference between a hobby and a special interest is the latter being an activity of unusually high intensity or focus. Degree of intensity is based on the amount of time the pupil will engage in the same activity (Attwood 2007, 173).

Henrik’s special interests were Star Wars, Minecraft, and wildlife-related facts, and these were his main focus when he was not in school. They were topics about which he could talk continuously. In addition, he showed a high degree of repetitive behaviour by telling funny stories over and over again, and thus boring his audience. Due to his difficulty interpreting non-verbal language and social interaction, Henrik was unable to recognise the signs of boredom in others caused by his repetitive stories and talk about own interests. Other topics, such as falling in love, leisure pursuits, own weekend experiences etc., Henrik perceived as uninteresting.

The cognitive style in individuals with AS/HFA differs from that of others. Pupils with AS/HFA will think and act in a concrete and literal manner. This is highly significant in respect of facilitating learning. To ensure that pupils like Henrik master school tasks, it is crucial that the teaching material is adapted to suit their learning style.

“The cognitive style involves a thinking pattern mostly based on own perspective, a focus on details, and a lack of interest in context. Details often become isolated phenomena where the pupil does not see the bigger picture or the context. Most individuals with AS have a cognitive style through which their ability to learn and understand is at its best when tasks and explanations are visualised.”

http://www.statped.no/globalassets/fagomrader/autisme/ve_as-handbok_laerertips_om_elever-med_asperger_syndrom-2013-10-04.pdf

Asperger syndrome – puberty and sexuality

Adolescents will usually obtain information and test their own knowledge on puberty, sexuality, and love through conversations with friends and by belonging to a social group. Individuals with AS/HFA are more likely than other young people to experience limited social interaction. They often struggle to understand the social cues and information shared between the young. Therefore, education on puberty, sexuality, and love will often have to be adapted and delivered in a different and more systematic manner to ensure adequate knowledge of these topics.

For individuals with AS/HFA, puberty may come as more of a surprise than for others. Due to a limited social network, their access to information is often more restricted than for their peers. Many with AS/HFA spend a lot of time on the internet. But how do they construe the information obtained? And which websites and topics do they find interesting? There are many poor-quality websites on sexuality online. Adolescents need guidance on how to obtain good information on sexuality and puberty. Explaining and preparing them for puberty is often left to parents and the school. This is a group of people who usually have a great need for predictability and certainty, and this may become problematic during such a transitional period.

Education on puberty and sexuality in school is usually delivered as classroom lessons or in groups. Many pupils with autism attend special educational needs groups, and will often miss the topic being taught in a traditional setting. From experience, we know that many with AS/HFA often are socially immature and not ready for the topic when presented at year-group level. We also know that individuals with autism have a different learning style than neurotypical children, and therefore require a different teaching approach. If then the topic itself is not motivating and interesting, the process becomes extra challenging. To talk about topics relating to sexuality and puberty to individuals with autism can be a pedagogical challenge.

Individuals with Asperger syndrome have the same sexual needs, urges, desires, similarities, and differences as other people. However, due to a difficulty communicating, a lack of experience, and problems with the social aspect, many misunderstandings may occur. (Jalakaas p. 114). To ensure that the information is understood, this material is presented in a concrete manner.

Sexuality

All humans are sexual beings. Sexuality is about discovering ourselves, our physical bodies and our emotions, and about self-perception and our relationship with other people. Sexuality is one of our most basic instincts. The need to explore our own body is a natural part of being human, and is a function that works independently of our intellectual and cognitive capacity.

Sexuality is an integral part of every human personality. It is a basic need and an aspect of being human that is inseparable from other aspects of life. Sexuality is not the same as sexual intercourse. It is not about our ability to have orgasms, nor is it the sum of our erotic life. These may be part of our sexuality, but not necessarily.

Sexuality is much more. It is the energy that drives us to seek love, warmth, and intimacy. It is expressed in what we feel, how we move, how we touch, and how others touch us. It is as much about being sensual as being sexual. Sexuality affects our thoughts, emotions, actions, and responses, and thus our mental and physical health. As health is a fundamental human right, sexual health must be a basic human right. (WHO's definition of sexuality.)

Everyone will move through puberty on their way to adulthood. This is a vulnerable time, marked by major changes. Nothing stays as it was. Puberty and sexuality are topics historically given little focus in school, and in particular for individuals who do not fall within the traditional "normal" range.

It is the responsibility of the support network to ensure that children and adolescents receive guidance and develop a healthy understanding of their own sexuality. The notion that people with intellectual disabilities or physical development disorders are asexual (not interested in sexuality) is a myth. It is important that sexuality is presented to children and adolescents in a gradual and positive manner.

Adolescents may already have a perception of sexuality obtained through TV, radio, music, and school friends. Our job is to ensure that the individual learns to like herself/himself, uses the correct language, and displays appropriate behaviour in terms of own sexuality when puberty approaches.

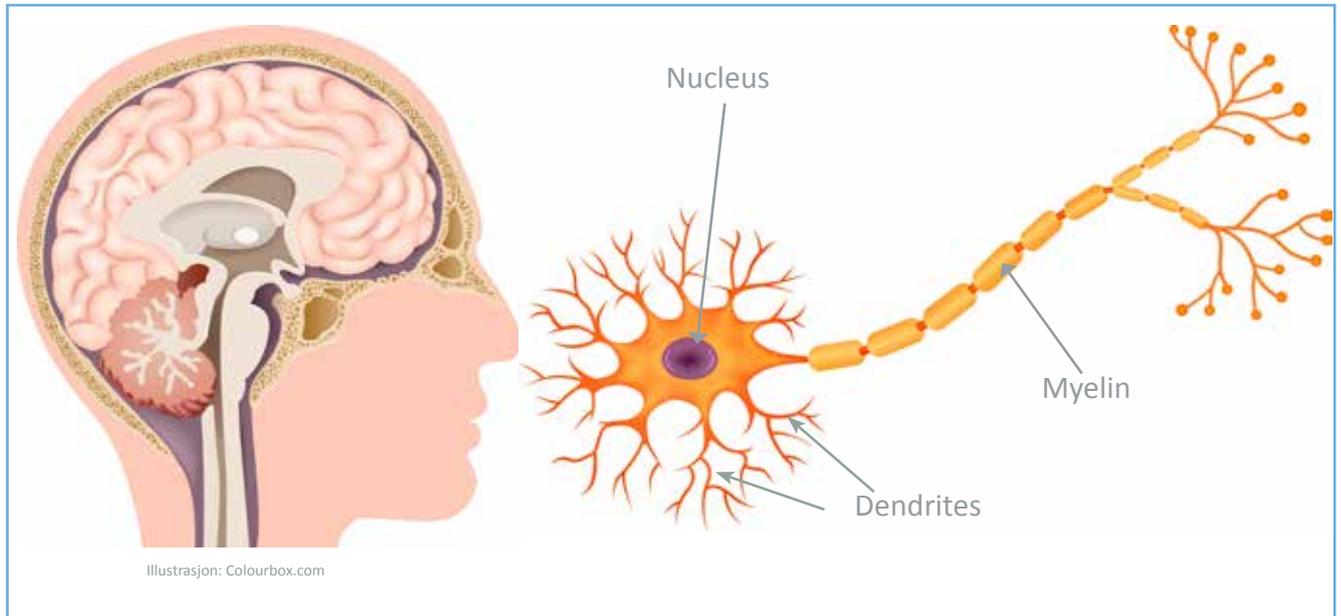
The brain remodelling process

Puberty brings numerous changes. One of the most significant transformations is what is happening in the brain. A comprehensive remodelling takes place during puberty, and this process may start as early as age 9 – 10. The brain of a teenager is almost the same size as that of an adult, but it is nowhere near fully developed.

In children, social functionality is located in the corpus striatum – an area in the centre of the brain. From puberty onwards, these functions gradually transfer to the frontal lobe. In the event of frontal lobe damage before age 10, the child's functions are retained in corpus striatum and are not lost. If frontal lobe damage occurs after puberty, these functions are lost. This transfer from a competent striatum to an immature frontal lobe takes time. In the long term, it is a smarter way to "organise" the brain.

The brain comprises numerous cells. These are linked together with axons. Around each axon, a myelin sheath is formed. This myelination means that a fatty layer is created around the axons and works as insulation. The illustration below shows a cross-section of the axons.

Cross-section of the fatty sheath (myelin) around the axon connecting the cells:



The frontal lobe cells are the last to become myelinated. When myelination is complete, the communication speed between the cells has increased. This myelination takes time; it is a slow process that lasts throughout puberty. It is not until we reach our early 30s that our frontal lobe is fully developed. Puberty is a kind of stabilisation phase for the frontal lobe, and during this period we see adolescents acting on impulse and taking risks. This can partly be explained by the frontal lobe not yet being fully formed; it is still being remodelled. On top of all this, there is a transfer of functions from corpus striatum to what will eventually become a competent frontal lobe.

In children, there is overproduction of brain cells and connections. During puberty, there is a need for a clean-up. This is a trimming process where cells that are not in use are removed. Unnecessary connections are done away with. Those that remain become stronger and faster, and those that are not in use will dwindle and disappear.

The frontal lobe is important for several functions. It is the area that controls thinking, behaviour, risk assessment, impulses, etc. Adolescents will often find it more difficult to control behaviour and manage their emotions. This may be linked to the area for such control not yet being fully developed.

Puberty is a vulnerable period. Early childhood experiences may have long-term effects on brain structure and cognitive functions. Encouraging awareness of own body and sexuality, and preventing abuse and negative experiences, will thus be important for a healthy brain – also in the years going forward.

Teaching plan guide

In the following is a short overview of how we envisage covering the various topics, with suggested links and tools that may be of use in combination with the subject areas. Pupils with AS/HFA often have a different way of thinking, and will require a modified approach. It is thus important that the person holding the conversations with the pupil is familiar with Part I to prevent misunderstandings that may occur in the communication between pupil and public health nurse, and also to prevent the pupil's behaviour being misconstrued.

Conversations can be held on a one-to-one basis or in a group. The teaching plan is primarily intended for use by public health nurses educating pupils with AS/HFA. This is because such health professionals have the expertise required to discuss puberty and sexuality, and have experience holding conversations about such topics with children and adolescents. If the teaching plan is used by a teacher or someone else, it is advisable to have a public health nurse present for guidance during the conversations. It is not recommended that parents deliver this programme. The topics may be difficult for parents and children to talk about, and it makes sense leave the systematic work presented in this teaching plan to specialists.

Any person holding the conversations should be qualified to deal with individuals with autism and their way of learning. If the public health nurse does not already know the pupil, it may be a good idea to talk to the teacher in advance to establish whether any special considerations are required and how the conversation best can be adapted to suit the individual.

As a general rule, we recommend that you always prepare well for the topics that form part of the conversation. This entails checking in advance whether the suggested websites are relevant and suitable for the pupil with whom you work. The various websites are also intended to guide the pupil to pages with good information for children and adolescents, and you should stop and check relevant links along the way. Individual approach to the various topics will always be required.

It is important to hold the conversation in surroundings in which there are no disturbances. A separate group room without any distracting sensory impressions, and without other pupils and teachers present, is crucial. This will help the pupil settle and feel at ease with the topic in question.

There is a natural follow-on from one topic to the next. However, it may not be necessary to complete all the conversations. The teaching of each topic should be dictated by the needs of the individual pupil. Sections that are not relevant due to age or gender, such as gynaecological examination, should of course be left out. Although the topic on girls and boys in puberty is relevant for all, it is natural to spend more time on the topic on girls when working with girls.

It is recommended that worksheets are printed and kept in a folder for the pupil to look at and take home as his/her personal file when the conversation has ended. There are room for breaks along the way to allow for reflection on the topics discussed. It is important to give the pupil a bit of time before moving on.

An individual with autism will often need longer to process information. To ensure that we do not move too fast, it is advisable to stay quiet for a few extra seconds before proceeding. We recommend having pen and paper available during the conversation. The comic strip conversations technique (a method developed by Carol Gray) is used to reinforce the meaning of the text along the way. These conversations features basic line drawings with speech and thought bubbles to which feelings are added. This method enables visual presentation of the communication forming part of a conversation. By dealing with one thing at the time, we move at a slower pace. As in a cartoon conversation, anything said, thought, and felt is added to the fields in the relevant order.

More information and examples are available in a handbook published by Statped. (www.statped.no 10.04.13)

http://www.statped.no/globalassets/fagomrader/autisme/ve_as-handbok_laerertips_om_elever-med_asperger_syndrom-2013-10-04.pdf

It can be useful to visualise by using basic drawings and figures to reinforce content that is difficult for the pupil to understand. Remember that for most individuals with autism, their visual receptiveness is far stronger than their auditory sense. Use fewer words and more illustrations.

Furthermore, it is important that those of us holding conversations with pupils do not moralise. Our aim is to adopt an attentive and approving attitude. When questions arise along the way, we will help the pupil if the subject area proves difficult. Some topics are repeated, but presented from a different angle – e.g. sweating in boys and girls. This is a topic revisited under hygiene. If it becomes evident that repetition is not necessary, you should skip to the next topic.

Should the pupil perceive the topic as uncomfortable/difficult, it may be helpful to take a break. Reassure the pupil that the topics are common for all young people. There should also be a strategy to allow the pupil to indicate that a break is needed if the conversation still is perceived as difficult, such as a “time out” sign. For some, it may be better to read quietly through the difficult topics by themselves.

Each section (except the first conversation) has a short summary of the previous conversation to ensure that the information has been understood. If necessary, help the pupil to remember by using the folder to look at worksheets from the previous session. Repetitions can be added to the plan if needed.

Each section ends in a similar manner to ensure that the conversations are predictable. This will instil confidence, and may encourage the child/adolescent to take more active part in the conversation. The duration and frequency of sessions, the degree of immersion in each topic, and which parts of the topics we choose, must be tailored to suit each individual pupil. However, exceeding 1 hour is not recommended, and the interval between conversations should not exceed 14 days to ensure continuity. Weekly conversations will be the most suitable choice for most. It is recommended that conversations with the pupil are held by the same person, unless a change is required due to special considerations.

Puberty and sexuality – an introduction

The first conversation is an introduction to the subject areas. During this session, we prepare an overview of the various topics to be discussed and when they will take place. This is to create predictability. We also clarify how much time we have for each conversation. Plans may change, and we inform of this during the first session. A print-out of the plan should be given to the pupil to bring home and study. The plan should also be added to the pupil’s digital calendar, e.g. under tutorials. Number of hours to complete the programme is established for each pupil.

During this first conversation, we reassure the pupil that the conversations are confidential. However, when we inform of our duty of confidentiality, it is important to specify that we on occasion have to break this if we identify circumstances of such a serious nature that other entities need to be contacted.

It is necessary and natural to let parents know that we are starting a teaching plan. Parents may be given a link to the teaching material. Information provided by the pupil during the process is confidential if the child is 16 years old or over. When the child is between 12 and 16 years old, information shall not be passed on to parents when the child, for reasons that should be respected, expresses a wish that it is not. Please see: <http://barneombudet.no/dine-rettigheter/>

Boys in puberty

Facial hair: It may be useful to bring examples of shaving equipment such as razor, shaving foam, creams, and other relevant items.

Deodorant: To reassure the pupil, maybe add a visit to a shop to look at what is available and where it can be purchased. Use a book on anatomy appropriate for the pupil's age when referring to genitals.

Girls and puberty

Bring concrete examples of sanitary towels and tampons of various sizes and uses (night pads etc.).

Maybe visit a shop to look at the selection available to reassure the pupil that this is common to buy.

Use a book on anatomy appropriate for the pupil's age when referring to genitals.

This conversation is heavy in terms of content. If necessary, it can be split into two sessions or more.

The degree of immersion in each topic must be assessed based on age, maturity etc.

Puberty and emotions

This is an introduction only to the topic of emotions and why mood-changes may occur during puberty.

It is recommended that the subject of emotions is looked at in a more systematic manner through weekly support conversations during primary and lower secondary school – for example by using the CAT-kit. The CAT-kit is a tool for Cognitive Affective Training. Individuals with autism may find it challenging to talk about their thoughts, feelings, and experiences. The CAT-kit contains a range of visual elements that may encourage communication around these topics. It enables us to help individuals with autism to better grasp social interaction and friendship, and to understand their own and others' needs and intentions through systematic training. Read more at <http://www.cat-kit.com/da/>

For anyone with school-age children, we recommend the following handbook from Statped:

<http://www.statped.no/Tema/Larevansker/Autismespekterforstyrrelser/Asperger-syndrom-Handbok--Informasjon-og-tips-til-larere-i-grunnskolen/>

Privacy

Unwritten rules and norms for what is private and what is public are often difficult for individuals with autism to understand. This area is covered by looking at when, where, and with whom it is appropriate to both talk about and engage in sexual activity. The pupil is expected to answer a range of questions. Act as secretary if necessary. Give a helping hand if the pupil finds it difficult to come up with good answers.

About finding a boyfriend/girlfriend

This section explains what a boyfriend/girlfriend is and with whom such a relationship is appropriate, and provides some advice on how to get in contact with someone you really like.

During this session, it is important that the person holding the conversation is familiar with the Rosa Kompetanse project promoting better understanding of sexual orientation and gender identity.

Always take an open-minded approach.

<https://llh.no/artikler/llh.no-rosakompetanse>

Contraceptives

This section looks at various contraceptives and their purpose.

It may be useful to bring examples of condoms, and also an artificial penis to show how they work. A trip to a shop where this can be purchased is training that may be added to this conversation.

Abuse

In this section, we look at what constitutes sexual abuse, how to prevent this happening, and how to raise the alarm. If you suspect that the pupil has been the victim of abuse, you have a duty to notify the child welfare services. It is possible to contact the child welfare services anonymously for advice. You can read more about how to handle concerns on this website:

<http://www.statensbarnehus.no/mistanke/?lang=nb>

Gynaecological examination

This section is intended as preparation for a gynaecological examination. The material is designed to reassure the pupil by explaining the procedure. It may be useful to provide the examining doctor with details of what the pupil has been prepared for, and to stay within the limits of what has been discussed. Add more detailed pupil information if necessary.

Sexually transmitted diseases

This section talks about the prevention of sexually transmitted diseases, and highlights the importance of using a condom during intercourse. If a sexually transmitted disease is suspected, it is important to refer the pupil to doctor for accurate diagnosis and treatment.

Hygiene

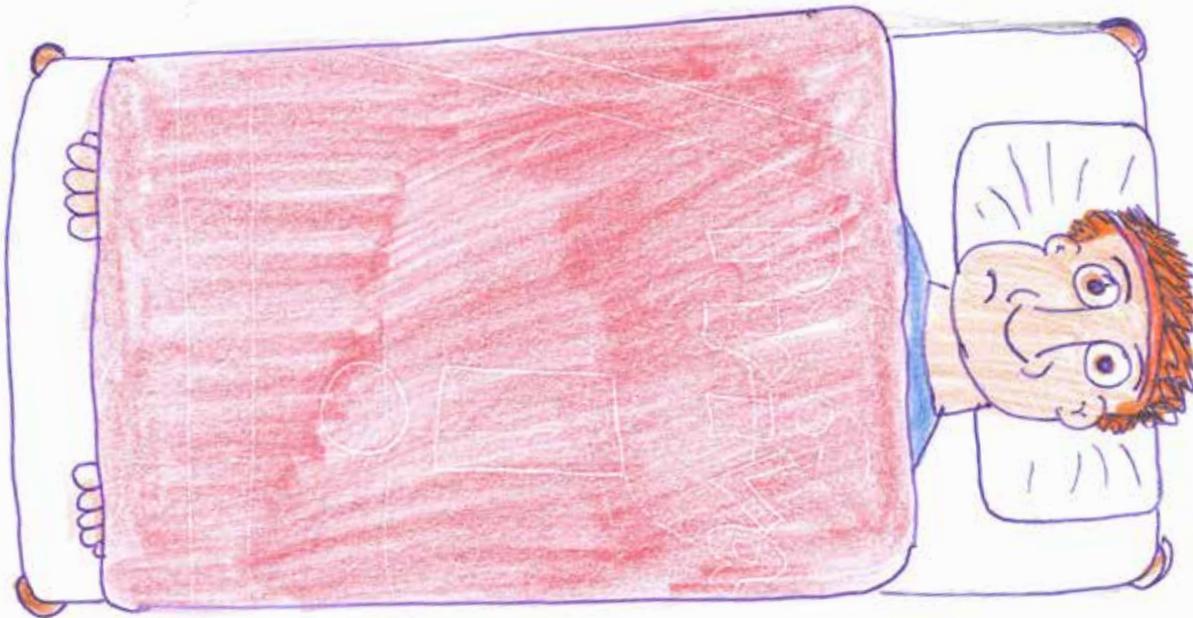
During puberty, hygiene becomes even more important. Many pupils with AS/HFA do not understand why they should change hygiene routines that, in their mind, already work well. In this context, it is important to provide information that has been adapted to and is appropriate for the individual. Sociale historier™ (social stories) may be a useful tool to ensure that the child receives information in a suitable manner. Again, it is important to tailor this around the needs of the individual. Examples of social stories are provided, but must be assessed to establish whether they can be used in their original format or should be amended to suit the individual pupil. To assess the quality and suitability of such stories, someone who knows the pupil well should review the material prior to use. You should familiarise yourself with this method in advance. A leaflet can be ordered from:

<https://www.yourvismawebsite.com/fjaran-granums-spisskompetanse-service/shop/product/hefte-6-sosiale-historier?tm=nettbutikk>

Final session

A final conversation is recommended to reiterate the topics covered. This is necessary as the topics often form the basis for a follow-on process. During this final review, new questions may arise. When topics are reiterated, it is useful to have the teaching plan at hand as a visual reminder of the information covered. This will make it easier for the pupil with HFA/AS to remember and to participate in the conversation. During this session, we also offer tips on further reading and links about sexuality.

The section includes some information on pornography, which is intended to make the pupil aware of the topic. We will refer to the website www.ung.no, where pupils can explore this topic by themselves.



Suggested reading for pupils

Relevant links

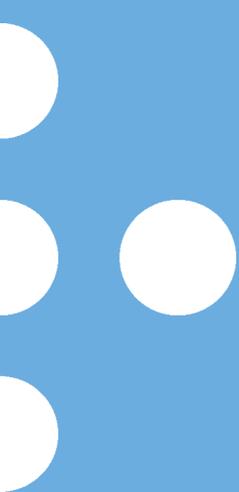
<http://nrksuper.no/super/newton/2015/01/30/nakne-fakta-om-pubertet/>
<http://no.wikipedia.org/wiki/Svette>
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