

# Health care on children's own terms



Thanks to all the children and young people who helped make this report possible!

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#### Introduction

Children's health is not just about protecting children against disease. Good health in children is about ensuring the physical, mental and social well-being of the child. Only when we have succeeded in safeguarding all of these factors can we talk about a good level of children's health. Norwegian children enjoy a health care service that is one of the best in the world, but what do these children and young people think about the services that are available to them? Do all Norwegian children really have equal access to good health services?

In the process of writing this report we discovered several serious shortcomings in the current provision of health care to children. Babies in neonatal units are not allowed to have their parents with them at all times, a right automatically enjoyed by older children by virtue of their ability to call out for their mothers and fathers. Young people in hospital often fall between two stools; hospital wards are tailored for either small children or adults. Very few children's wards have the expertise and resources to identify and assist children who have been exposed to violence and sexual abuse. All too few children who have been exposed to violence are being examined by doctors, something that undermines their legal protection as well as their chances of receiving help for serious health issues.

As adults, we can pick up the phone and book an appointment with our GP or a specialist when things take a turn for the worse. When children need help with their problems they have to knock on a school health services door that is all too often closed. Children's low-threshold health services are grossly under- prioritised in many municipalities. Children from refugee backgrounds often struggle under the burden of mental health issues. Far too many of these children are not identified, and the kind of assistance they need is too fragmented and difficult to access.

The UN Committee on the Rights of the Child's General Comment no. 15 concerning the child's right to the best available health services states several significant points regarding the State's responsibility to safeguard the health of the child. The Committee on the Rights of the Child instructs the State to develop good primary health care services for children, especially in schools. Service availability should be nationwide and vulnerable children are to be given special consideration.

The Committee on the Rights of the Child is aware that the State holds overall responsibility for ensuring the health of the child, even though this work is carried out in the municipalities. The State's responsibility entails safeguarding resources but also monitoring the quality of services and providing opportunities to submit complaints where services are inadequate.

The Committee on the Rights of the Child is also preoccupied with the child's right to be heard within the health service, as individual service users but also during the process of designing service provision.

We are nowhere near good enough at involving children as service users and experts in the health care arena. How can we build good school health care services or aftercare services for children and young people who have been exposed to violence and abuse without listening to the experiences and wishes of these children?

It is my hope that this report will inspire everyone working in children's health to involve children and young people in the process of developing good health services for children – children's health on children's terms!

Many thanks to everyone who contributed. An extra big thank you to the children and young people who gave us valuable information about their experiences as users of health services for children. Without their voices and stories this report would be inconsequential.

### Remarks to the english version of the report

The Norwegian report was released in March 2014. This version in English is an abbreviated version of the report. Positive changes in many of the areas mentioned have taken place during the year that has passed since the report was released.

For example: The school health service has received many more resources. Many hospitals are about to establish Youth Councils and the government is writing a strategy for young people's health. Several hospitals have also decided to establish family-oriented sections within neonatal intensive care units. Moreover, the Minister of Health has asked the hospitals to prioritize positions allocated for social pediatric work.

Anne Lindboe, The Ombudsman for Children

June 2015

anne hindboe



Meetings with children

### Meetings with children

rticle 12 of the UN Convention on the Rights of the Child (CRC) states that children have the right to be heard in matters affecting them and that the views of children shall be given due weight. Children and young people are the real experts on being children and young people. At the same time, adults are the ones making decisions for them. Consequently, it is easy for adults to overlook both minor and major aspects of services for children, especially in relation to services for vulnerable groups.

The Ombudsman for Children makes a distinction between "expert meetings" and "expert groups". Expert meetings refer to relatively short, one-off meetings with groups of young people. These meetings may centre on a topic we are currently especially concerned about. We often hold such expert meetings before a conference, e.g. a meeting at a school, visit to a youth club etc. The meetings usually last between one and four hours.

Expert groups are groups made up of children and young people all of whom have had experiences of a certain issue and who will work on key points together with Ombudsman advisors over a period of time.

The Ombudsman for Children has put together a handbook on how to involve children as experts which can be found on our website. We encourage you, the readers of this report, to get children and young people actively involved in your work: this leads to real participation and effective services for children.

The Ombudsman for Children holds expert meetings and expert groups to give children and young people with different experiences the chance to be heard, so that their views and experiences will be considered when the authorities make decisions that will affect the group of children in question. In addition, we have a permanent Youth Panel that provides input to our work and makes recommendations about the kinds of issues we should be working on. The Youth Panel has also provided ongoing input to our work with "Health on Children's Terms".

For this project we have made use of both expert groups and expert meetings. We met with several children to hear about their experiences with health services for children. We talked to around 170 children in total.

In addition to the meetings with children we also met with a number of researchers, health workers and others working within children's health.

This report is not a research paper. It is first and foremost composed of contributions from children regarding what can be done to improve the creation of health services on their terms. The report also contains assessments and recommendations from The Ombudsman for Children based on the information we gathered during the project.



Children's right to health according to the CRC

### Children's right to health according to the CRC

n this part of the report, we present a brief summary of the aspects of international law that have particular relevance to the project. The UN Convention on the Rights of the Child (CRC) is part of Norwegian law, something that gives it substantial weight. The Convention's provisions must take precedence over any other conflicting legislative provisions.

The UN's Committee on the Rights of the Child monitors the implementation of the CRC in Norway. In this report we refer specifically to their recommendations to Norway as well as to their general comments regarding how the CRC should be interpreted.

#### **Obligations of the CRC**

The right of the child to access health care is incorporated in several international conventions by which Norway is bound. The most relevant of these is Article 24 of the CRC.¹ It is commonly thought that this provision gives children the right to health, while in actual fact it confers on children the right to essential health services and protection against acts which may be detrimental to their health.²

#### CRC, Article 24

Article 24, no.1 sets out the provisions overarching aim - that children shall have the right "to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health". This entails that the authorities must put in place the most optimal conditions possible to enable the child to develop a good standard of health. The UN's Committee on the Rights of the Child specifies that in assessing expectations pursuant to Article 24, the child's biological, social, cultural and financial requirements must be taken into consideration.3 At the same time, the State's obligation must be seen in the context of national resources and level of development. The authorities should take all possible and reasonable action based on

conditions within the individual country. In our report we refer to, among other things, the fact that conditions in several neo-natal intensive care units are far from optimal.

Article 24, no. 2 lists the more concrete objectives and mandates that the State is obligated to implement. Primary health care is emphasised in b). The Committee on the Rights of the Child is unambiguous in its assertion that the authorities must prioritise access to primary health care. This means, among other things, that in organising the health service, special arrangements for low-threshold services must be made. Within several chapters of this report, the Ombudsman demonstrates that school health services do not function at an acceptable level in Norway.

Article 24, no. 2 a) directs the Norwegian authorities to take appropriate measures to reduce infant and child mortality. This report outlines the significance of this in terms of how neo-natal intensive care units in hospitals are organised around the country and the ramifications this has for children at the neo-natal stage.

#### CRC, Article 4

Article 24 must be seen in connection with Article 4 of the CRC which obligates the State (the Norwegian authorities) to undertake all necessary measures in order to adhere to the CRC. Article 4 specifically states: "...all appropriate legislative, administrative, and other measures for the implementation of the rights recognized in the present Convention." In its General Comment, no. 5,4 the Committee on the Rights of the Child mentions a number of measures that are required for effective implementation of the Convention: development of special structures, monitoring, training and other activities within public administration, the legislature and the court system. The Norwegian authorities are, among other things, obligated to organise health

care in such a way as to provide children with genuine access to essential health services. This has relevance for many of the areas we looked at in this report.

### Limitation of State obligation in terms of social and economic rights

Article 4 indicates – as does Article 24 – a limitation on the obligations of the State in terms of economic, social and cultural rights. The State is obligated to undertake measures "...to the maximum extent of their available resources." In other words, the requirement is for systematic implementation in correlation with the resources the country has at its disposal. The right to health in the CRC constitutes a highly ambitious goal, and countries like Norway cannot, in the same way as developing countries, de-prioritise children's health services citing insufficient resources on the part of the authorities.

The Norwegian authorities' ability to meet the requirement in Article 4 "to the maximum extent of their available resources" will depend on whether there is political will to prioritise children and whether the authorities have an effective management system in place. The authorities must be able to demonstrate that they are taking all possible action to provide children in Norway with the best possible health care and that the level of services provided exceeds a commonly defined minimum standard. At the same time, in a highly developed country like Norway, there may be medical treatments that the public health service cannot be expected to provide.

#### Other provisions of the CRC

Articles 4 and 24 must be seen in the light of the rest of the Convention, not least the basic principles in Article 2 (non-discrimination), Article 3 (the child's best interests), Article 6 (the right to life and development) and Article 12 (the right of the child to be heard).

The State is particularly obligated to give special attention to the most deprived groups of children. The non-discrimination provision requires that Norway, among other things, actively monitor those groups of children who may be reliant on special measures to be able to exercise their right to health. In this report, children with refugee backgrounds form a group for whom special measures should be in place.

Also within health care, the best interests of the child (the CRC's Article 3) must be a guiding principle in all decisions, whether we are dealing with children as a group or on an individual basis. The Committee on the Rights of the Child states that in assessing the best interests of an individual child in relation to health matters, one must consider his/her physical, emotional, social and educational needs, age, sex, relationship with parents or other carers, family and social background. The Committee on the Rights of the Child recommends that the State create clear guidelines and procedures for health professionals, which set out how a best interests assessment in relation to health matters should be carried out.7

Not least one has to listen to the child's views pursuant to Article 12 in order to be able to determine the best interests of the child. The Committee on the Rights of the Child has highlighted the importance of the child receiving information and experiencing participation the process. This report shows that Norway has a lot of room for improvement in relation to involving children in hospitals, developing the school health service and services to children in vulnerable situations.

The right to health is closely related to another guiding principle: Article 6 on the right to life and development. A number of underlying factors connected to a child's development are decisive for the child's ability to achieve optimal levels of health. The Committee on the Rights of the Child mentions among other things relationships within the family unit and the local community. Neglect and violence in close relationships are emphasised as especially decisive in terms of the child's ability to develop a good level of health. The ability of the authorities to fulfil Article 19 – which requires the authorities to protect children against violence and assault – therefore has a direct impact on the health of the child.

The Committee on the Rights of the Child also points out that the authorities should adopt a "child health in all policies" strategy. All measures must be implemented to remove the bottlenecks that hinder transparency, coordination, cooperation and accountability in all services impacting the health of the child.<sup>10</sup>



A reasonable standard of school health care?

#### A reasonable standard of school health care?

School health services form a separate statutory health care service for school children. School health services, with school nurses at the forefront, do not exist only to administer vaccinations or offer advice on nutrition and contraception. The school nurse can also be a significant adult for children in a number of ways. She is often experienced as a non-threatening adult to whom children can talk when life gets challenging. The school nurse can listen; she can give advice and put children in touch with other services where she deems this necessary. This entails a high degree of preventive health care work.

Article 24 of the CRC emphasises the responsibility of the State party and the municipality to provide children and young people with qualitatively sound and sufficient health services. The Act relating to Municipal Health and Care services explicitly mentions school health services as a part of the municipality's preventive health care and health-promoting services. Specifically calling attention to this service in legislation gives a clear message that such services play an integral role in a feasible health service for children and young people.

For many years the Ombudsman has been in doubt as to whether school health services are being properly staffed. Several children and young people have given us some worrying input about the situation at their schools.

We are aware of the variations that exist between municipalities and between different schools, but generally speaking: Are school health services in as bad a state as we are being led to believe? And if so, what has to be done to get them up to a standard that ensures reliable and acceptable services for children and young people. In this part of the project it was important for us to find out more about the services we often recommend to children and young people.

#### Method

To obtain information about how school health services function, the Ombudsman spoke to children and young people about their experiences. In total, we conducted 12 expert meetings with children all over the country. The young people came from both large and small municipalities. Some of the groups were randomly put together based on the schools the children attended. Others were formed on the basis of experiences with using school health services. We also obtained information from children who had taken part in the Ombudsman's expert groups of children who have been exposed to violence and sexual abuse and children from refugee backgrounds.

Additionally, we looked at research on the topic and spoke to professional and research communities and a range of organisations and public bodies.

### School health services in the pupil's sphere

School health services are located in schools, in the pupil's sphere. Around half of the pupils at lower and upper secondary school make use of the services. The services are intended to be low threshold; students can drop in without an appointment, avoid long waiting times and are not charged for services. This means that school nurses and other service personnel have a unique opportunity to meet and assist every child and young person where he/she is, on their terms and irrespective of their background.

The service facilitates early detection of problems and reaches all children and young people irrespective of social background. Early intervention in the problem development phase means that a child experiencing difficulties – whether at school, with friends or at home – is able to get help quickly.

### Pupils want accessible school health services

"Don't tell me to go and see the school nurse because she isn't here!"

According to the pupils, current provision of school health services is inadequate, due to, amongst other things, that many of the school nurse have waiting lists. Some pupils have to wait two to three weeks. Many school nurses are not at the school every day. At some schools the nurse is never there at all.

"Come and see me next week at 2pm." – it's not okay, but that's kind of how it is now.

In only one of the Ombudsman's 12 expert meetings, the young people stated that the school nurse was available because she was at the school every day.

"I talk to my mother in the evening, but it's better to talk to the school nurse about bullying." "I haven't had the chance to talk to the school nurse because she's only at school every second week and usually just to give injections."

The pupils would like the school nurse to be at school every day. However, this is not always enough. In large schools several staff members may be required to follow up the children in need of help from school health services.

### Recommendations for school health services from pupils:

- School health services must have enough staff
- The school nurse has to be at school every day

### Pupils would like more information on services

A study conducted by Sykepleien<sup>14</sup> shows that school nurses are unable to carry out their statutory duties and definitely do not have time to spend on outreach or information work. We see this reflected in conversations with pupils.

Many of the pupils we spoke to would have liked school health service personnel to interact more with pupils during breaks and in class. They thought that school nurses should provide more information about the kinds of things they and other school health service personnel can help with, and how they can assist pupils receive other kinds of help.

The pupils also called for better communication between school health services, other support services in schools and teachers. The pupils' opinion was that school health services are made worse by generally poor levels of communication.

### Recommendations for school health services from pupils:

- The school nurse must visit the classrooms and generally have a higher profile among the pupils.
- The school nurse must tell pupils what she can help with and what children can talk to her about. Let the children know that it's OK to go to the school nurse.
- The school nurse has to inform pupils about her duty of confidentiality but also that sometimes she has to take things further.
- The school nurse has to follow up pupils from primary one onwards.
- The school nurse should talk in a "child-friendly" way and should not use complicated language.

#### The Ombudsman's recommendations:

- School health services must actively approach children and young people and inform them about available services, their duty to report and duty of confidentiality.
- School health services must have sound procedures in place for working together with pupils, school staff and municipal health personnel.

#### Pupils want more expertise

School health services have a unique opportunity to interact with children and young people, give them advice and help them with the issues they are struggling with. Both children and young people face many different challenges with friends, at school or at home. Many pupils also have to cope with mental and/or physical health issues.

Precisely because of these challenges it is perhaps not surprising that the pupils that the Ombudsman talked to wanted to see higher levels of expertise among school health service personnel. They were particularly focussed on the need for school nurses to have more expertise when it comes to mental health issues.

#### Mental health issues

The pupils thought that generally speaking school nurses need to have more expertise on young people and mental health. They told us that lots of young people struggle with mental health problems and that many drop out at upper secondary level due to this. Several pupils talked about the stressful nature of young people's everyday lives.

"Stress in everyday life is a huge problem. Young people are generally very stressed."

Research also shows that the current generation of young people takes school seriously, but are perhaps more stressed than previously. There is a tendency towards increased anxiety, sleeplessness and hopeless feelings when thinking about the future among a relatively large proportion of young people. School health services will therefore be an important factor in preventing those children and young people with problematic everyday lives from developing even more serious problems.

School health service personnel themselves report that many children and young people are struggling with mental health issues.<sup>16</sup> The current estimate is that 70,000 children and young people within the age range 3-18 have the kind of problems that qualify as mental illness.<sup>17</sup> We also know that around half of all mental illnesses strike before a child turns 14 years of age.<sup>18</sup> In addition, estimates show that between 15 to 20 percent of children between 3 and 18 years of age have impaired function due to symptoms of mental illness such as anxiety, depression and behaviour disorders.<sup>19</sup>

It is natural to assume that a school nurse will sooner or later come into contact with the majority of these children. It is therefore worrying that the children and young people themselves think that school nurses should have more expertise within mental health.

Some of the children think that school health services should have a psychologist.

"There are some things we don't want to talk to the school nurse about. We need a psychologist too."

The Ombudsman believes that school health services should employ or have access to a psychologist, perhaps a clinical pedagogue.

"Those who really need mental health care should have access to it every day. Too many pupils are walking around uncertain about their situation."

#### Violence and abuse

The children and young people who have been exposed to violence or sexual abuse thought that school nurses need to have more knowledge about these issues. Many of the children we talked to had seen a school nurse in connection with violence or abuse coming to light. It is common for children to tell a friend first, and for the friend to then tell an adult, in many cases a school nurse. It is therefore of great concern that so many children have had bad experiences in their encounters with school nurses. A small number of children described the school nurse as understanding, as someone who took charge of the situation in a positive way, someone who knew a lot about sexual abuse. But the majority of the children we talked to said that the school nurse had very little knowledge about violence and sexual abuse and that she failed to deal with them in an acceptable way.

"She did not seem interested. She didn't know anything about abuse and didn't ask any questions."

"It was like talking to a brick wall."

When the school nurse is disinterested or fails to get involved it is easy to see why children who have been exposed to violence or abuse do not feel taken care of.

#### School health services have to refer pupils

Our impression is that school health services are being left to handle a lot of responsibilities, including duties for which they are not necessarily qualified. An important part of the preventive work of school health services is therefore to identify those in need of specialist health care and refer them to the appropriate bodies.

In addition, the school nurse must also have a solid understanding of when her duty of confidentiality becomes applicable. School nurses must not sit on the information that a child is not receiving adequate care or has been exposed to violence or abuse. In such cases child welfare services and, where appropriate, the police must be contacted. It is unacceptable that they are being left too long with responsibilities they are neither qualified for nor authorised to handle.

"School nurses have to know about the different bodies and use them. If you promise to do something, you have to do it right away. I'm waiting."

#### The pupils recommendations on what school health services should be able to do:

- School health services personnel must have expertise in and knowledge about psychology, mental health in young people and violence and abuse.
- They have to know who can help the child/young person.
- School nurses must be good at talking to children and young people.
- School health services must include several occupational groups and work together with others.

#### The Ombudsman's recommendations:

- Municipalities must map out the competence need within school health services when they
  plan preventive health care work.
- Municipalities must offer good health services to children and young people, with sufficient levels of expertise in general mental health work, mental health work aimed at children and young people from refugee backgrounds and children and young people who have been exposed to violence and abuse.

### A gap between full-time equivalent and recommended standard

Pursuant to the CRC, municipalities have a responsibility to ensure that children and young people have access to good quality and sufficient health care services. In its General Comment No. 15, the UN Committee on the Rights of the Child recommends that universal access to primary health care for children should be prioritised and provided as close as possible to where the child and his/her family live, i.e. in the local community.

The Committee believes that health care services in schools provide an important opportunity for health-promoting work and increases the accessibility of health services to children.<sup>20</sup> This is also a fundamental principle in safeguarding primary preventive work and contributing to the promotion of good standards of health among children and young people.<sup>21</sup>

Currently, school health services in many places are only able to provide the most essential services, have long waiting lists and little opportunity to represent a genuine low-threshold service for children. The Norwegian Directorate of Health has stipulated a recommended minimum

standard. The standard indicates the number of school nurses that must be employed in order for school health services to be able to fulfil their statutory duties. The Directorate of Health estimates that a shortage of as many as 1500 posts within school health services prevents the achievement of this standard. Achievement of the minimum standard is estimated to cost between 560 and 800 million kroner.

In 2014, 180 million kroner was granted for reinforcing school health services. However, one study shows that under half of this amount has gone into strengthening these services. The municipalities have spent this money on other services. This highlights the importance of earmarking any new funds for school health services. Earmarking means funds must be used for a stated purpose. The Ombudsman also believes that the quality of school health services must be safeguarded by making the minimum standard legally binding. This means that the authorities will have a statutory obligation to meet the stated standard.

#### The Ombudsman's recommendations:

- The authorities must set a legally binding minimum standard in terms of the number of school nurses that must be employed in primary, lower-secondary and upper-secondary schools.
- School health services must receive earmarked funds.
- School health services must be supplemented by multiple occupational groups.
- A service run on children's and young people's terms

### A service run on children's and young people's terms

Article 12 of the CRC asserts the right of children and young people to participate and express their views in matters that affect them. The UN Committee on the Rights of the Child recommends in General Comment No. 12 that children must be given the opportunity to express their views during the planning of services related to the health and development of children. However, our experience is that children and young people have no direct influence on the municipal processes involved in designing satisfactory municipal health care services.

Children and young people are the end-users of school health services. This means that they have key knowledge about their own needs and how these may be met by school health services. The children and young people we talked to had significant views on availability, capacity, levels of expertise, information and how good

school health services should function. In order for the municipalities to be able to plan the shape of current and future school health care services, it is undoubtedly necessary to collate the experiences of the children and young people themselves.

Information from those working within school health services and research on children's and adolescent health will also contribute towards understanding the importance of focussing on preventive work and school health services.

#### The Ombudsman's recommendations:

- The municipalities must actively involve children and young people in planning school health care services.
- Children must be interviewed during internal checks and inspections of municipal health services.

## The Ombudsman's recommendations for a reasonable standard of school health care

### The Ombudsman's recommendations to the school health service:

- School health services must actively approach children and young people and inform them about available services, their duty to report and duty of confidentiality.
- School health services must have sound procedures in place for working together with pupils, school staff and municipal health personnel.

### The Ombudsman's recommendations to the minicipalities

- Municipalities must map out the competence need within school health services when they plan preventive health care work.
- Municipalities must offer good health services to children and young people, with sufficient levels of expertise in general mental health work, mental health work aimed at children and young people from refugee backgrounds and children and young people who have been exposed to violence and abuse.

- The municipalities must actively involve children and young people in planning school health care services.
- Children must be interviewed during internal checks and inspections of municipal health services.

### The Ombudsman's recommendations to the state authorities

- The authorities must set a legally binding minimum standard in terms of the number of school nurses that must be employed in primary, lower-secondary and upper-secondary schools.
- School health services must receive earmarked funds.
- School health services must be supplemented by multiple occupational groups.
- A service run on children's and young people's terms



**Children in hospital** 

### Children in hospital

uring certain periods, some children spend more time in hospital than they do at home. These children usually have a diagnosis or functional impairment that requires frequent treatment and observation for different lengths of time.

The Ombudsman has received messages of concern from both personnel and other parties about conditions in the neo-natal intensive care units of several hospitals. This prompted us to take a closer look at how these units function.

A few years ago, the Ombudsman established an expert group of children who were hospitalised.<sup>24</sup> The children passed along information about what it was like to be a young person aged between 13 and 18 in hospital. We realised that it was important for us to find out more about their situation.

For this part of the report we took a closer look at how hospitals look after the youngest and oldest child patients.

#### Legislation

Article 24, no. 2a) of the CRC directs the Norwegian authorities to take appropriate measures to reduce infant and child mortality. This makes it natural to investigate how neo-natal intensive care units in different hospitals are organised and adapted for infants. For the older children in hospitals, the CRC's provisions on the right of the child to be heard are important. Article 12 grants children the right to be heard in all matters affecting them. To what extent is this right being observed in terms of young people in hospital?

Children in hospital have special rights by virtue of their status as children.<sup>25</sup> These rights also apply to young people and children in neo-natal intensive care units. For the youngest children, the right to be accompanied by at least one parent during their hospitalisation<sup>26</sup> is central. Parents

are also to be given the chance to attend while the child is receiving treatment provided this does not complicate the treatment. The provision does not mention anything about how long the child is allowed to have his/her parents with him/her at any one time. But it confers on the child the right to company during the entire period of hospitalisation.

For the oldest children, it is a question of the hospital recognising that young people have particular needs. The hospital environment should be organised in a way that motivates young people to look after their own health. Young people also have the right to be kept active and stimulated. Activities must be age and developmentally appropriate.<sup>27</sup> In addition, young people must be heard and given opportunities to influence their everyday life during the period of hospitalisation.

#### Method

To obtain information about children in neonatal intensive care units, we contacted parents who have or have had children hospitalised within such departments. It is the parents, along with specialists who are the newborn baby's spokespeople in this report.

We listened to the young people in different ways. On our visits to hospitals we always tried to come into contact with young people, including the ones in adult wards. However, it has not been easy for our contacts in the hospitals to locate them.

One of many explanations for this is that young people in adult wards "disappear" somewhat within the hospital system.

In addition to the young people who are hospitalised, we met with the Youth Council at Akershus University Hospital and Oslo University Hospital. We held expert meetings with young people who have spent a lot of time in hospital. We also had meetings with several organisations and visited nine hospitals. We administered

a questionnaire to the children's wards of all Norway's hospitals. 17 of 20 children's wards answered questions about conditions for young people and for children in neo-natal intensive care units in their hospital.

#### Children in neo-natal intensive care units

Newborns who are ill or who were born prematurely<sup>28</sup> are put into special wards, usually called neo-natal intensive care units. Every year, between 3000 and 6000 newborns are placed in such wards all over the country. The majority of these infants are premature (born too early).

Premature babies and newborns that are ill are especially vulnerable and particularly dependent on their caregivers being able to see and interpret their signals. The early establishment of this interaction has significance in terms of the quality of care the child receives. The UN Committee on the Rights of the Child has stated that the first year of life is significant for the child since it lays the foundation for his/her mental and physical health and emotional security.<sup>29</sup>

#### **Conditions for children**

The Ombudsman's experience is that the majority of units, apart from one of the neo-natal intensive care units we visited, are facing challenges related to cramped and/or impractical premises. Several children are placed in the same room allowing very little space between incubators.

For an infant to be together with his/her parents the parents have to sit on a chair next to the incubator. The parents also need to have accommodation elsewhere within the hospital complex. This means that infants are not able to be with their parents 24 hours a day.

As well as limited space, noise and stress levels are other distancing factors which are often highlighted. Many sources describe the general noise and stress levels around the children as high.

"There's constantly something going on around you – talking, shouting, rattling, beeping..." Although the Ombudsman is aware that several neo-natal intensive care units have established one or more family rooms, only one of the hospitals is family-oriented. In other words, the ward is organised such that parents and children can spend quiet time together in a separate family room 24 hours a day.

"It was only when we came to a family-oriented ward that he lifted his head for the first time. It was like he got the energy to investigate his surroundings."

A mother, who was in a family room with her child, told us that it was during the period that her son was really small and seriously ill that he responded most positively to skin-to-skin contact. Personnel also highlighted the importance of skin contact for the youngest and most seriously ill children.

"Children you thought weren't going to survive improved when they were able to lie skin to skin."

### Conditions for parents in neo-natal intensive care units

Many parents naturally experience having a premature and/or seriously ill baby as both frightening and emotionally exhausting. Parents and professionals tell us that parents in crisis and experiencing uncertainty can sometimes distance themselves from their child – both physically and emotionally. They can be scared to touch and hold their baby and some are reluctant to form strong emotional bonds with their child.

The parents experience the professionals they have met as capable and caring. However, conditions in the hospitals are described as extremely cramped and ill-suited for children and

parents being together. This influenced how often they were together with their children and the quality of the interaction.

"It's hard to sit in a straight-backed chair several hours a day, day in, day out."

Several parents also said they had to leave their children during doctor's rounds, which could take several hours. It was explained that the high number of children in the same room made this practice necessary in order to adhere to duties of confidentiality amongst other things.

"It felt completely wrong not to be able to be there during doctor's rounds - it concerns your child after all."

Another factor that was emphasised by many was the emotional strain experienced in being exposed to everything that takes place in the room and that does not involve one's own child.

"It's not OK when you have to sit so close together and struggle with your own child and there's an emergency christening going on at the next incubator."

### Family-oriented neo-natal care is best for children

Family-oriented neo-natal care builds on the principle that a child's parents are his/her most important caregivers, and recognises the child's right to be with his/her parents. In purely practical terms, this implies that the child, wherever possible, will be with his/her parents 24 hours a day. Incubators will be used as little as possible and all medical treatment will be administered at the mother's or father's chest. A technique called KMC ("Kangaroo Mother Care") is often used.<sup>30</sup>

More information is needed about this, but research suggests that family-oriented neo-natal care probably has a positive effect on the child's development, not just in medical terms, but also physiologically and psychologically. It is easier for the child to maintain a stable temperature and he/she is less exposed to stress so is able to allocate energy to growth. Amongst other things, the method has been seen to reduce mortality rates and the risk of serious infection in children. In addition, milk production and breastfeeding is easier for the mother. The child grows faster, both in relation to weight, length and head circumference.31 Studies from Sweden also suggest that the Kangaroo technique contributes to making fathers in particular feel secure and that it makes it easier for them to come to terms with the new, completely unexpected situation they find themselves in.32

"When they lay the baby on the father's chest - that's it! Dad will stay with the baby until he/she is discharged."

-A paediatrician on how fathers can be involved

One father we met believed he was given his child back when the child was moved from a general

neo-natal intensive care unit to a hospital that practised family-oriented neo-natal care.

"I used to visit my child before; now I'm a father."

### The current number of family-oriented wards

In our questionnaire to the hospitals, we asked if a family-oriented neo-natal intensive care unit had been established, whether there were plans in place to establish such a unit and, if so, within what kind of timeframe. Many of the hospitals had plans to create multiple family rooms but only three of the 17 hospitals that responded had plans to establish family-oriented neo-natal intensive care units as described above.

The Ombudsman has observed that many neonatal intensive care units are organised in a way that calls into question whether they have achieved the optimal standard for children, cf. Article 24 of the CRC.<sup>33</sup> We are also concerned about the possibility that the way in which the units have been organised could constitute unacceptable practice.

In connection with the project, the Ombudsman reported Oslo University Hospital to the Chief County Medical Officer. We requested an evaluation of whether the children were being provided with an acceptable level of health care. The Chief County Medical Officer concluded, among other things, that the children's right to be together with at least one parent was not being fully observed. The hospital also received criticism connected to patient security and the day-to-day running of its neo-natal intensive care unit.

The documentary evidence that exists on the many advantages for the child of being treated in a family-oriented neo-natal intensive care unit should justify this type of unit being the rule and not the exception.

#### Young people in hospital

Young people fall under the category of health services for children and/or adults but are seldom referred to as a separate group. At the same time we know that adolescence is a period all about

breaking free, finding your own identity and being granted permission to be young.

Young people form a particularly vulnerable group that often receives an inferior level of service to children and adults. This is partially connected to a lack of knowledge about one's own rights as an end-user/patient and existing service provision and also to young people as a group not insisting on their demands<sup>34</sup> It was therefore important for us to investigate how young people are taken care of while they are in hospital.

#### The Ombudsman's recommendations:

- The Ministry of Health and Care Services should require hospitals to build familyoriented sections within neo-natal intensive care units.
- In anticipation of a new construction etc, the hospital should be required to draw up specific plans on how it is going to lay the groundwork for family-oriented neonatal care.
- National guidelines should be compiled for neo-natal intensive care that guarantees the child the opportunity to have his/her parents with him/her during his/her entire stay, in line with other children in hospitals.

### Only one of three children's wards has an 18-year age threshold

Pursuant to the CRC, until you turn18 years of age, you are a child. Children younger than 18 years of age must, where possible, be placed in children's wards.<sup>35</sup> Our investigation shows:

- Only one of three children's wards has an 18-year age threshold
- Some hospitals place children as young as 13 years old in adult wards

This means that young people lose out on the special follow up they are entitled to by virtue of them being children. For example, parents cannot be around to the same degree in an adult ward and there are few to no leisure activities tailored for children. Because there are fewer members of

staff per patient in an adult ward, it is not as easy to ensure that young people are keeping up with their schoolwork.<sup>36</sup>

"I was in the adult ward. I was in a wheelchair. I was treated like a really old lady there."

Many of the young people we talked to said that the transition from the children's ward to the adult ward was difficult. The Ombudsman's questionnaire showed that very few hospitals have written procedures to safeguard the child's needs when they are moved to an adult ward.

#### The Ombudsman's recommendations:

- All children's wards should have an 18year age requirement for transfers to adult wards.
- All hospitals must establish written procedures for transfers from children's wards to adult wards.

### Medical personnel must treat young people equally

The young people pointed out how important it was for doctors to interact with them appropriately. Are doctors and medical personnel less trusting of young people than of other age groups? Many of the young people have set ideas about this:

"It's harder for doctors and others to trust young people."

Young people are not children and they are not adults, they are in a phase of life where they will become motivated and learn that they are the ones responsible for their own health, not their parents and not the doctor.

"One bad encounter can make you back off completely and never want to go back."

They would like doctors to show an interest in more than just their condition/illness. Young people would also like doctors to put aside some time to talk to them alone without their parents being there.

Pursuant to Article 12 of the CRC, children have the right to be heard, and in accordance with the Patient's Rights Act, children shall be given the chance to express their views in all matters concerning their own health from the age of 12.<sup>37</sup> The Ombudsman therefore considers it important for young people to also be given time alone during doctor's rounds and check-ups. Not only will this help them learn to take responsibility for their own health and illness but they will also be given the opportunity to talk about any difficult situations they may be experiencing at home.

"What's really important is the way things are said; the way you tell people things. Think about their age and the words you use. They can't say "you got here in the nick of time" like they said to me when I was told I had cancer."

#### The Ombudsman's recommendations:

 Young people must be given time alone during doctor's rounds and when they attend check-ups together with their parents.

#### Influence of young people in hospital

During the transition between childhood and adulthood, young people have to learn to take responsibility for a number of areas, including their own health. It is therefore crucial that they are able to exert influence over how health services for their age group are organised.

Article 12 of the CRC states that young people have the right to express their views and be heard. The Committee on the Rights of the Child has also emphatically asserted that it is the responsibility of adults to lay the groundwork for this to happen.

Young people have a lot of experiences that can contribute to a smooth transition from child patient through adolescent patient to adult patient. In addition, young people can make good, experience-based recommendations for both the running and development of health enterprises.

Our meetings with young people, our visits to hospitals and our questionnaire have confirmed our theory that young people have very few opportunities to be heard and exert influence over their own everyday lives in hospitals. This confirms what other investigations have reported.<sup>38</sup>

At the time of writing this report, there were only two hospitals in the Oslo area that had established a youth council. One of the hospitals stated that "involving young people in their own health/treatment produces more competent and more effective health service users, decreases the risk of future complications and improves quality of life for young people and families." Now several hospitals around the country have established or are in the process of establishing this.

#### The Ombudsman's recommendations:

- All hospitals must establish their own youth councils.
- The youth council should be established centrally within the hospital system, in the same context as existent patient councils.

#### Future focus on young people's health

There are many capable hospital personnel who are proficient at helping young people in hospitals but the Ombudsman sees no comprehensiveness in the work being done with young people. All age groups are entitled to the best possible assistance and observation in hospitals. However, we would maintain that young people need that little bit extra that allows those in vulnerable situations to conclude their treatment with a positive feeling.

The Committee on the Rights of the Child encourages State parties to establish a youth-friendly health service with personnel and facilities adapted for young people.<sup>39</sup> In many Western countries, "adolescent health" constitutes a separate category. The World Health Organisation (WHO) has long taken an interest in young people's health.<sup>40</sup>

It is high time we established young people's health as a separate health category in Norway too.

#### The Ombudsman's recommendations:

- The health authorities must put together a strategy for young people's health.
- The health authorities must compile a guide to the ways in which services can work with young people's health.
   Information from young people should be gathered during compilation of the guide.

Here we present ten recommendations from young people to medical personnel. The recommendations are intended for general medical personnel, not just for those working in hospitals. The recommendations have been summarised by the Ombudsman from consultation with the Ombudsman's youth panel, the youth council at Akershus University Hospital, the Ombudsman's expert meeting with young people with experience of hospitals and from an online survey.

## 10 recommendations - to medical personnel from young people

- 1. Be cheerful, friendly and accommodating
- 2. Speak clearly, but not like you would to children. Also remember: there's a difference between a 13-year-old and a 17-year-old.
- 3. Give information about our illness and treatment to us, not just our parents.
- 4.Be prepared and read our records, don't make me repeat my medical history again and again.
  - 5. Don't just talk about illness, talk about other things too. Ask us how we're feeling.
- 6. Don't make us wait too long for our appointment, our time is also important.
  - 7. With respect comes trust.
- 8. Take into account that we are not always used to doctor's appointments. Be patient and give clear information.
- 9. Physical and mental presence are two different things.
- 10. Take us seriously and let us finish what we have to say. Believe what we say. There's no such thing as a stupid question.

## The Ombudsman's recommendations on children in hospital

### Premature and sick children in the neo-natal intensive care units

- The Ministry of Health and Care Services should require hospitals to build familyoriented sections within neo-natal intensive care units.
- In anticipation of a new construction etc, the hospital should be required to draw up specific plans on how it is going to lay the groundwork for family-oriented neonatal care.
- National guidelines should be compiled for neo-natal intensive care that guarantees the child the opportunity to have his/her parents with him/her during his/her entire stay, in line with other children in hospitals.

#### Influence of young people in hospital

- All children's wards should have an 18year age requirement for transfers to adult wards.
- All hospitals must establish written procedures for transfers from children's wards to adult wards.

- Young people must be given time alone during doctor's rounds and when they attend check-ups together with their parents.
- All hospitals must establish their own youth councils.
- The youth council should be established centrally within the hospital system, in the same context as existent patient councils.

#### Future focus on young people's health

- The health authorities must put together a strategy for young people's health.
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   Information from young people should be gathered during compilation of the guide.



Health care services for children who have experienced violence and sexual abuse

## Health care services for children who have experienced violence and sexual abuse

n this part of the report, we look at some of the key sections of health care services for children who have experienced violence and sexual abuse.

Children who have been exposed to violence and sexual abuse are a particularly vulnerable group. It is vital that they encounter health care services that are at once able to uncover abuse, secure evidence in the event of criminal proceedings and take care of the child – in both emergency situations and in the longer term.

The Ombudsman looked specifically at the medical follow-up children receive and posed the following questions:

- Are there satisfactory emergency medical services available to these children?
- Are all children in need of a medical examination provided with one on arrival at a Children's House?
- Do hospitals have a sufficient number of paediatricians and do personnel have the skills required to take care of this group of children?
- Are there satisfactory follow-up services for children who have been exposed to violence and sexual abuse?

#### Legislation

The CRC's Article 19 instructs the State party to take all appropriate measures to protect children against violence and sexual abuse. The provision asserts that such protective measures should, among other things, include effective procedures for examination, treatment and legal assistance where required.

The UN Committee on the Rights of the Child has stated that the CRC's Article 24 (1) imposes on the State party a strong obligation to ensure that relevant health services are available to all children. The State party must identify and eliminate any obstacles that stand in the way of children receiving medical assistance.<sup>41</sup> The Specialist Health Service Act, § 2-2 and the Health Care Act, § 4-1 require that a reasonable level of service is provided. This entails, among other things, organisation and expertise.

#### Method

For this subproject, the Ombudsman established two expert groups of children who had experienced violence or sexual abuse. <sup>42</sup> There were 11 children in total within the age range 11 – 17. We did not go into detail in terms of their stories but we talked about the kind of follow-ups they had received after the violence/sexual abuse had been uncovered. The children made specific recommendations aimed at personnel who encounter children in similar situations.

We also discussed the topic with a number of professionals and held meetings with representatives from various organisations, unions and research communities. We visited seven hospitals where the issues we addressed included staffing and expertise in dealing with violence and sexual abuse. In addition we administered a questionnaire to the paediatric departments of all national hospitals.

#### Impact on health

Children who are exposed to violence or sexual abuse can suffer from both physical and mental health problems as a direct result of the abuse. Many studies also show that experiencing violence

or sexual abuse in childhood may have a serious impact on the victim's health in adulthood. 43 Violence and sexual abuse against children is a public health issue and a significant societal problem. It is estimated that domestic abuse costs Norwegian society between NOK 4.5 and 6 billion per year. 44

### Are satisfactory emergency medical services available to these children?

The current situation is that many children who have been exposed to violence or abuse never get examined by a qualified doctor. A thorough medical examination is important; both to secure evidence in the case of criminal proceedings and to ensure that the child receives the necessary protection and medical assistance. When such examinations do not take place, one worst case scenario is an abused child not being believed and being sent back to a potential abuser.

The Ombudsman believes all children who have been exposed to violence or sexual abuse must be offered a medical examination undertaken by doctors who are qualified social paediatricians, i.e. they have specialist expertise in the field of violence and abuse against children. Experiences from the project show that there is no consistent emergency medical service for children who may have been exposed to violence or abuse. There are major geographical variations in terms of the institution to which the child is sent, whether the service is staffed around the clock and whether the personnel admitting the child have specialist expertise in dealing with violence and abuse against children.

The children we talked to have had varying experiences with the emergency services. Many of them had not contacted the health service at this stage. Some had visited casualty departments and had acceptable experiences there. At the same time, they said they were treated like adults and that at times it was difficult to understand what was going on. A girl in one of the Ombudsman's expert groups experienced having to wait several hours with a public health nurse after she reported having been sexually abused because nobody knew where she was supposed to be examined.

"It's important that you get medical help right away. It's important to get proper information and to be told what's going to happen during the examination and what's going to happen afterwards."

-Girl in expert group

### Children's referral centre for violence and sexual assault

The Ombudsman believes that a dedicated referral centre for children connected to hospitals with large paediatric departments should be established. The centres will have an important function both in carrying out medical examinations on children. Moreover, the centre will provide guidance for health personnel at the hospital and within the health service in relation to violence and sexual abuse against children.

Standard procedure would be to transfer a child to a referral centre in cases where the child may have been exposed to a certain level of violence or sexual abuse. In other, less serious cases, telephone consultation between the casualty department/GP and the referral centre should be routine. The referral centre will also be a resource centre that other bodies, e.g. child welfare services, can contact for advice.

#### The Ombudsman's recommendations

- A dedicated children's referral centre for violence and sexual assault should be established and connected to the hospitals with the largest paediatric departments.
- All children who have been exposed to serious levels of violence or sexual abuse should be examined by specialist health personnel as soon as possible.

### Medical examinations at Children's Houses

The Children's Houses constitute a service for children and young people who may have witnessed or been exposed to violence or sexual abuse in cases where a report has been made to the police. The objective of establishing the Children's Houses was to provide a comprehensive service to these children. This entails that services are co-located in one place and that the services come to the children, not the other way round. As of March 2014 there are ten Children's Houses in Norway.

The Children's Houses arrange for the child to be interviewed, provide guidance and follow up the child and his/her next of kin. In some cases a medical examination of the child is carried out. These examinations take place at the request of the police, or sometimes child welfare services. The paediatricians who conduct the examinations are not employed by the Children's Houses but are recruited from hospitals for this specific purpose.

On average, only 13% of all children who came to the Children's Houses in 2012 were given a medical examination,<sup>47</sup> but there are significant variations between Children's Houses in terms of numbers of medical examinations.

In the Ombudsman's expert groups, only a few children had received a medical examination at a Children's House. Many of them thought that this was a service that everyone should be offered, not least to get reassurance that everything was normal and to be able to ask questions about difficult issues. Afterwards, many still had questions about their bodies that had not been answered or that had taken some time to be answered.

"Everyone should be offered a medical examination. Also to get the chance to ask about anything you're wondering about."

-Girl in expert group

It is particularly important that a child who has not previously been examined is offered a thorough medical examination at a Children's House. Additionally, when a child has already been medically examined, the Children's House should obtain confirmation that the examination was carried out by a qualified professional.

#### The Ombudsman's recommendations:

- All children who come to a Children's House must be offered a medical examination unless this is not deemed to be in the best interest of the child. The reason for this must be stated in all such cases.
- Regional health authorities must ensure that there is sufficient numbers of specialists to meet the demand for medical examinations at Children's Houses.

### Expertise and capacity within the health care service

Violence and sexual abuse is demanding both medically and, not least, emotionally. It is therefore important that sufficient time and resources are allocated to training and education. Moreover, it is important that there are sufficient numbers of social paediatricians to examine the children and that health personnel in general receive regular professional updates on the topic irrespective of where they work.

### The specialist heath service – too few social paediatricians in hospitals

Social paediatricians are doctors with specialist expertise in examining and following up children who have been exposed to violence and sexual abuse. That a child is examined by a doctor with this kind of expertise can be a decisive factor; both in terms of uncovering exposure to abuse and securing evidence in the event of criminal proceedings.

The Ombudsman asked all the paediatric departments in every major Norwegian hospital how many paediatricians they have allocated to social paediatric work. The responses show that

very few posts are specifically dedicated to this type of work. Most hospitals reported between zero and one post. Oslo University Hospital had the highest number, 2.5 posts, which reflects a recent increase.

In the same questionnaire we asked paediatric departments whether there were plans in place to extend social paediatric services. 59% answered "no". Given the current low level of staffing this is extremely worrying.

The Norwegian authorities are obligated, pursuant to Article 19 of the CRC, to undertake all appropriate action in order to protect children against violence and abuse, including putting in place conditions that provide satisfactory levels of protection and follow-up to children. It is a cause for concern that the health care service has been organised in such a way that there are virtually no social paediatricians available to conduct examinations, a procedure that constitutes an essential factor in providing children with the protection to which they are entitled.

#### The Ombudsman's recommendations:

- All larger-sized paediatric departments must have a minimum of one post allocated to social paediatric work. More than one post would be preferable.
- All paediatric departments should have an interdisciplinary social paediatric team consisting of paediatricians, nurses, social workers, psychologists/ child psychiatrists, and, where necessary, responsible professionals from other involved departments.
- All departments that deal with children should have at least one member of staff with responsibility for cases involving violence and sexual abuse against children.

#### **Expertise in the health care service**

The Ombudsman's hospital questionnaire shows that even though many hospitals have some internal training programmes on violence and abuse, the scope of these varies. The training should encompass not just the paediatric departments but also any other departments that deal with children, for example surgical and orthopaedic departments. Also problematic is the fact that not all hospitals appear to have adequate internal procedures for detecting cases in which a child may have been exposed to abuse. In<sup>48</sup> other words, there is a need for more expertise within and better organisation of the service.

The Ombudsman is aware that there are a number of sound procedures for cases of child abuse to which reference may be made. For example, the Norwegian Centre for Violence and Traumatic Stress (NKVTS) has created a handbook for health personnel for use in cases of suspected physical abuse.<sup>49</sup>

It is not just the specialist health service that needs more expertise on violence and abuse. The primary health care service, encompassing GPs, casualty departments, and school nurses in the school health service and public health centres are pivotal in detecting children who have been exposed to violence or abuse. The children in the Ombudsman's expert groups reported different experiences with school nurses. As one of the children put it:

"I don't think the school nurse knows much about violence. I think she's better at giving injections and treating cuts."

Several children experienced that their school nurse was not particularly knowledgeable about violence and sexual abuse and what she was supposed to do with the information the children gave her.

The foundation for the expertise of health personnel is laid down during education. In its 2013 strategy document, "Childhood Comes But Once", the Government announced that there will be an increased focus on violence and sexual abuse within several major educational programmes. However, medical school was not mentioned, so the Ombudsman sent an enquiry to the medical faculties. The responses it received showed that course coverage of the topic varied. Taking into account the vastness, complexity and importance of this issue, the Ombudsman believes that there must be more integration of the topic of violence and sexual abuse in medical school.

#### The Ombudsman's recommendations:

- Establishing mandatory courses on dealing with violence and sexual abuse during the residencies of all medical graduates working with children.
- There should be one standard procedure for child abuse that is applicable to the entire hospital and all relevant departments.
- Mandatory courses on dealing with violence and sexual abuse must be established for casualty department doctors and GPs.
- School nurses' skills in identifying children and young people who have been subjected to violence and sexual abuse must be enhanced.
- Municipalities must have satisfactory health services for children and young people, with sufficient expertise within mental health services aimed at children who have been exposed to violence and abuse (see chapter on school health services).
- The medical faculties must ensure that the topic of violence and sexual abuse receives sufficient focus throughout medical school.

#### Follow-up services – input from children

It seems an obvious statement of fact that children who have been exposed to violence or sexual abuse will be in need of some form of follow-up. But what kind of help children need depends on what they have experienced, the duration of the offence, the perpetrator of the offence, the child's specific reaction to the violence/sexual abuse and the opportunities open to the child for support from his/her caregivers.<sup>50</sup>

Article 19 (2) of the CRC states that the State party is obligated to protect children against violence and sexual abuse including "effective procedures for the establishment of social programmes to provide necessary support for the child" and "other forms of ...treatment and follow-up".

Current treatment and follow-up services for children exposed to violence are marked by a lack of comprehensiveness. There is an obvious need for more knowledge about the kinds of treatment options available and how they work.

The Ombudsman's two expert groups have a lot of experience with various follow-up measures. We emphasise the children's experiences and recommendations in this area and urge the Government to listen to children who have been exposed to violence and sexual abuse when designing services for these children. The recommendations are also of relevance for individuals and professionals. The children's experiences and recommendations concerning school nurses are discussed in the chapter on school health services.

### How to interact with a child who has been exposed to violence or sexual abuse

Both expert groups were very concerned about how they were initially received. Many of the children stated that chaos ensued after their experiences were revealed. They would like to deal with adults who are calm but also committed and caring. They call for professionals who have a personal and caring demeanour.

#### The children's recommendations on dealing with children:

- When a child tells you about violence or sexual abuse, don't react in such an extreme way.
   Don't cause a commotion. Be clear and calm. The child may be under the impression that what he/she has been through is completely normal.
- When meeting adults who are there to help, it's important to feel safe, prioritised and supported.
- Be careful about the kind of words you use don't use words/phrases like "poor you", "feel sorry for..." or "shame". Let the child define things.
- Show commitment, compassion and concern.
- Be personal and show that you care.

#### Information

The children were very clear that they wanted to be kept informed about what was happening. For example, several of the children had developed a poor relationship with their school nurse because she had passed on information without notifying the child in question. Afterwards the children realised that it was a good thing the school nurse took things further even though they did not want her to do so at the time but they wished they had been given an explanation as to why it was necessary. They also wanted to be involved in deciding how this would be done. The UN Committee on the Rights of the Child has also highlighted the importance of children being kept properly informed about health-related matters.<sup>51</sup>

### The children's recommendations on how information should be given:

- Keep the child fully informed at every stage. Tell him/her what is going to happen and why. Make sure the child understands what is happening.
- Explain why you have an obligation to pass on information about what has happened – and let us be involved in deciding how information will be passed on.

#### Physical surroundings are important

It is obvious that the physical surroundings at the location where the child is to receive help are extremely significant. Both expert groups stated that pleasant surroundings are essential. This is about creating a space in which the child feels welcome and safe.

### The children's recommendations for surroundings:

 The places we go to get help have to be comfortable and well ventilated – with nice bright colours and good chairs.

### Children's and Young People's Mental Health Outpatient Clinics

Many children who have experienced violence or sexual abuse are currently referred to Children's and Young People's Mental Health Outpatient Clinics (BUP). It is important that children are given the option of mental health follow-ups because emotional, mental health and psychosomatic complaints are often the things that make life difficult for children in the long term.

BUP consistently scored badly in terms of helping the children who participated in the Ombudsman's expert groups. The children said that the BUP therapist demonstrated little understanding or respect. They would have preferred the person dealing with them to show more personal commitment to their cases. Interaction with the therapist was experienced as impersonal and unrewarding by many of the children.

The children also felt that the therapist had limited knowledge about violence and sexual abuse and consequently failed to give them adequate help. Many of the children mentioned that the BUP therapist went over and over what had happened, which was not helpful. They felt that they were given very little concrete advice about what they could do to make things better going forward.

"They just tell you to stop thinking about it. I want advice about what I can actually do!"

The way psychiatric health care for children and young people currently functions is ill-suited to a lot of children who have experienced violence and sexual abuse and are in need of follow-up services. The general focus is on diagnosing and disease. A statement from one girl illustrates this:

"I didn't feel ill before I came to BUP."

Many of the children from the expert groups experienced that BUP focussed too much on diagnoses, diseases and issues.

"At BUP I think that they ask questions and dig around to find a diagnosis they can pin on you."

"You just have to get a diagnosis and then you'll get help with the problem. But maybe I don't even need a diagnosis."

Children who have been exposed to violence or sexual abuse do not necessarily have any clear symptoms, neither is it a given that the right thing to do is to give the child a diagnosis. The child and his/her family may nonetheless have a substantial need for some form of follow-up.

We should be careful about making generalisations based on such a small group of children. But the Ombudsman has also received other negative feedback about BUP services to this group of children, from children, parents and professionals alike. The Ombudsman is therefore concerned about whether BUP is able to offer these children the kind of follow-up services they need.

Many of the children in the expert groups had experienced better treatment elsewhere. including at the Children's Houses. Asked why they felt better taken care of there, many children answered that the people they encountered there seemed genuinely interested in them. They showed the right amount of commitment, compassion and consideration. The children also emphasised that the Children's Houses were cosy and they felt that everyone was seen and taken care of. They did not have to talk about the things they had experienced if they did not want to. It was also good to meet and get support from others who had experienced similar things. It is clear that the way in which children are treated from the very start is highly significant in terms of how they experience follow-ups.

#### The children's recommendations to BUP:

- Take time to get to know the child and create an atmosphere of trust and safety. To do this you have to be committed, attentive and give of yourself.
- BUP has to change their way of thinking and stop focussing exclusively on diagnoses. A diagnosis can make me feel worse and I might still need help even if I don't have a diagnosis.
- Let me tell my own story and decide what I want to tell you and what my needs are.
- Just because you have read my referral papers, don't assume that you know me and my story.
- We would rather wait a bit longer to be able to speak to someone who knows a lot about violence and sexual abuse.
- Don't focus so much on the things that are problems look ahead.

#### Organisation of support services

The children we talked to thought that follow-up services should be more flexible. They do not want to just sit in a room and talk. It was mentioned that BUP has become too old-fashioned in the ways they work.

The Ombudsman supports the children's view that there should be flexible services that can be experienced as more accessible to children than is currently the case. This is in line with the

recommendation from the UN Committee on the Rights of the Child that the State party put in place a holistic system that safeguards the child through the provision a wide range of services. <sup>52</sup> Instead of operating on the basis of current support services and trying to slot these children into existing services, an analysis should be conducted of what these children actually need and services organised accordingly.

#### The children's recommendations on how support services should be organised:

- The people who are supposed to help us must be available in different ways than they are today. We want to be able to call whenever we need to talk.
- We want to be helped where we need it, by someone with specialist knowledge of violence and sexual abuse.
- It is important that the different bodies know about each other and can help each other.
- The authorities must ensure that the experiences and wishes of children are presented during the process of organising and designing services for children who have been exposed to violence and sexual abuse.

#### The Ombudsman's recommendations:

The authorities must ensure that the experience and wishes of children are presented during the process of organising and designing services for children who have been exposed to ciolenve and sexual abuse.

## The Ombudsman's recommendations on health care services for children who have experienced violence and sexual abuse

### Children's referral centre for violence and sexual assault

- A dedicated children's referral centre for violence and sexual assault should be established and connected to the hospitals with the largest paediatric departments.
- All children who have been exposed to serious levels of violence or sexual abuse should be examined by specialist health personnel as soon as possible.

#### On Children's Houses

- All children who come to a Children's House must be offered a medical examination unless this is not deemes to be in the best interest of the child. The reason for this must be stated in all such cases.
- Regional health authorities must ensure that there are sufficient numbers of specialists to meet the demant for medical examinations at Children's Houses.

### The specialist heath service – too few social paediatricians in hospitals

- All larger-sized paediatric departments must have a minimum of one post allocated to social paediatric work. More than one post would be preferable.
- All paediatric departments should have an interdisciplinary social paediatric team consisting of paediatricians, nurses, social workers, psychologists/ child psychiatrists, and, where necessary, responsible professionals from other involved departments.
- All departments that deal with children should have at least one member of staff with responsibility for cases involving

- violence and sexual abuse against children.
- Establishing mandatory courses on dealing with violence and sexual abuse during the residencies of all medical graduates working with children.
- There should be one standard procedure for child abuse that is applicable to the entire hospital and all relevant departments.

#### On expertise in the health care service

- Mandatory courses on dealing with violence and sexual abuse must be established for casualty department doctors and GPs.
- School nurses' skills in identifying children and young people who have been subjected to violence and sexual abuse must be enhanced.
- Municipalities must have satisfactory health services for children and young people, with sufficient expertise within mental health services aimed at children who have been exposed to violence and abuse (see chapter on school health services).

#### On medical school

 The medical faculties must ensure that the topic of violence and sexual abuse receives sufficient focus throughout medical school.

#### On organisation of support service

 The authorities must ensure that the experience and wishes of children are presented during the process of organising and designing services for children who have been exposed to violence and sexual abuse.



The health situation for children at reception centres for asylum seekers

## The health situation for children at reception centres for asylum seekers

hildren from refugee backgrounds often have special needs and their experiences in or while fleeing from their home countries may have an effect on their mental health. In Norway, the first place the majority of asylum seekers will live is at a reception centre. A number of studies have been conducted to chart the different aspects of living conditions in such places. Nevertheless, there is a lack of systematic, documented information in Norway concerning the impact on children's health of living at a reception centre for longer periods of time. In this part of the project we decided to take a close look at how a child's health may be affected by living at a reception centre for an extended period. In addition we looked at how the mental health of children from refugee backgrounds is safeguarded when they are settled in a municipality. Moreover, we evaluated how the Norwegian Immigration Appeals Board (UNE) treats their medical records when assessing appeals concerning residence permits. However, due to space limitations, only the section dealing with children at reception centres has been translated into English.

#### Legislation

The UN Convention on the Rights of the Child (CRC) imposes on the Norwegian authorities the responsibility of tailoring health care services for children from refugee backgrounds. Article 24 of the CRC gives all children the right to health care, and in General Comment no. 15, where it interprets Article 24, the Committee on the Rights of the Child writes that States Parties have a responsibility to ensure that "barriers to children's access to health services... should be identified and eliminated.<sup>53</sup>"

Article 2 of the CRC asserts that these rights shall apply to all children within the jurisdiction of the State party, implying that children who do not have residence permits are also entitled to health care in Norway.

#### Method

In this part of the project, the Ombudsman's personnel had discussions with a total of 25 children within the age range 5-18. All the children we talked to came from refugee backgrounds. The majority of them have been granted residence permits in Norway, while some do not have residence permits. Some of them were unaccompanied refugee minors; others came to Norway with their families.

In addition, we talked to several professionals who work with children and young people from refugee backgrounds, within the health care service, local government and child welfare services.

### How is children's health affected by living at reception centres for extended periods?

A frequently used image of modern day reception centres is that of a "waiting room". Reception centres for asylum seekers are not meant to be permanent places of residence. This is reflected in the emphasis by the authorities on reception centres should constitute a "very simple level of accommodation". <sup>54</sup> Children make up a large proportion of residents in reception centres (21 percent in 2013). <sup>55</sup> In October 2013, 3969 children were living at reception centres. <sup>56</sup>

"We lived at a reception centre for two years. We only had two rooms and it was very cramped – there are six of us in our family. We were so young – seven and nine years old. We didn't understand much. What was the worst thing about it? There was no football field. The courtyard was dirty. People dropped trash and cigarette ends everywhere."

The children talked about the waiting and the uncertainty. Waiting for a response or receiving a rejection were not discussed much by the families, even though these issues affect their lives. The children talked about how they feel when they think about what the future might hold:

"I have sad thoughts and I get angry."

"If we talk about it, everybody gets sad."

The children we met in connection with this project believe that it is important they get a prompt response to their applications for asylum, and that those who are granted residence permits are settled quickly in municipalities. The authorities must know that they feel sad when they get rejections and that they need to be given help right away. This supports the research findings

of studies on the living conditions of children at reception centres.<sup>57</sup>

The majority of recent research that has been conducted on the health of children at Norwegian reception centres for asylum seekers appears to focus on unaccompanied minors. But a study carried out in Denmark indicates that children who have lived for over one year at a reception centre have an increased risk of developing mental health conditions. Life at reception centres is characterised by waiting, isolation, passivity and, in some cases, absence of a personal life and influence over one's everyday existence.

"Waiting is hard, the whole family worries about it, they have thoughts. It's difficult to think about what is going to happen."

It is natural to assume that a long stay will increase the strain on children. In a report based on a Swedish study of the situation for asylum seekers, the waiting period is described as one of the main issues.<sup>60</sup>

In many other areas, institutionalisation has gradually been abandoned because of its detrimental effect on children. But we allow children from refugee backgrounds to live for years in institutions on the margins of society without actually knowing what the consequences might be. The goal must therefore be to substantially reduce waiting times at reception centres. This implies both shorter processing times and faster settlement, but also quicker repatriation of families with children when it is apparent that there are no grounds for them to remain in Norway. Although this may appear brutal, it may be better for the children than living with uncertainty for extended periods of time.

#### Children's health issues

The experiences of experts working in the field of childhood/adolescent mental health indicate that the absence of ordinary everyday life may lead to health issues in children. <sup>61</sup> Common reactions include tension, fear, depression, sleep problems, bedwetting, memory/concentration/learning problems, aches and pains, behaviour disorders, self-mutilation and deficient regulation of affect. Many children are also traumatised and tormented by posttraumatic stress reactions.

We have found sufficient indications to suggest that extended stays at reception centres for asylum seekers have a negative impact on the health of children, but there is little definitive information about the direct cause and scope of the issues. Such information is a prerequisite to be able to prevent children living for extended periods at reception centres from developing health problems.

### The right to access to kindergarten and upper secondary school

We know that activity and play are important factors in children's health. The municipalities we spoke to told us that kindergarten too is important in terms of giving children the opportunity to learn good Norwegian and in detecting children in need of help. Children living at reception

centres in Norway are not entitled to a day-care place. The Ombudsman considers this practice discriminatory.

All children who have lived in Norway for more than three months have the right to primary and lower secondary education. However, children aged between 16 and 18 who do not have a residence permit are not entitled to upper secondary education. This means that many young people aged between 16 and 18 who live at reception centres are left without access to education or other daytime services. This can make children extremely passive, and many of our sources have highlighted this as potentially detrimental to health.

In June 2014, after this report was published in Norwegian, Parliament amended the Education Act so that children waiting to have their applications for asylum processed now have the right to upper secondary education. However many young people remain in Norway after receiving a final rejection of their applications for asylum. These children are still not entitled to upper secondary education.

#### The Ombudsman's recommendations:

- Research must be conducted into the health-related consequences for children of living at reception centres for extended periods. The children themselves must be informants.
  - Measures must be implemented to reduce waiting times for children at reception centres, including:
    - Measures that ensure that families understand that a final rejection means that they have to leave the country
    - Measures that ensure that those who are granted residence permits are settled quicker

#### The Ombudsman's recommendations:

- All children must be given legal entitlement to kindergarten, irrespective of residence status.
- Young people must be given legal entitlement to upper secondary education, irrespective of residence status.

# The Ombudsman's recommendations on the health situation for children from refugee background

#### On research and gatering information

 Research must be conducted into the health-related consequences for children of living at reception centres for extended periods. The children themselves must be informants.

#### On children's health issues

- Measures must be implemented to reduce waiting times for children at reception centres, including:
  - Measures that ensure that families understand that a final rejection means that they have to leave the country
  - Measures that ensure that those who are granted residence permits are settled quicker

### On the right to access to kindergarten and upper secondary school

- All children must be given legal entitlement to kindergarten, irrespective of residence status.
- Young people must be given legal entitlement to upper secondary education, irrespective of residence status.

#### Notes

- 1. The UN convention on social, economic and cultural rights article 12 apply to children. The Committees practice is of interest when determining the content of the CRC.
- 2.Halvorsen & Aasen (2012) *Barns rett til helsetjenester.* p. 187 in Høstmælingen, Kjærholt, Sandberg (red) Barnekonvensjonen, Univeristetsforlaget
- 3.UN Committee on the Rights of the Child General Comment no. 15 para 23, CRC/C/GC/15
- 4.General comments are the Committees opinion on how the CRC should be interpreted on any given subject. The comments are not legally binding.
- 5-Smith(2012) FNs konvensjon om barns rettigheter in Høstmælingen, Kjærholt, Sandberg (red) Barnekonvensjonen, Univeristetsforlaget
- 6.Halvorsen & Aasen (2012) *Barns rett til helsetjenester.* p. 187 in Høstmælingen, Kjærholt, Sandberg (red) Barnekonvensjonen, Univeristetsforlaget
- 7.UN Committee on the Rights of the Child General Comment no. 15 2013 para 14, CRC/C/GC/15
- 8.UN Committee on the Rights of the Child General Comment no. 15 2013 para 19, CRC/C/GC/15
- 9.UN Committee on the Rights of the Child General Comment no. 15 2013 para 17, CRC/C/GC/15
- 10.UN Committee on the Rights of the Child General Comment no. 15 2013 para 99, CRC/CGC/15
- 11. The Act relating to Municipal Health and Care services  $\S 3-1$
- 12.An expert meeting is when children or young adults give the Ombudsman for Children information about a particular issue.
- 13. Public Health Report Good health a common responsibility White paper. Meld. St. 34 (2012–2013) Ministry of Health and Care Service
- **14.**www.nsf.no/vis-artikkel/1125453/17036/Helsesostreslaar-alarm:-Helseministeren-og-KS-maa-paa-banen
- 15.Hegna, K, Ødegård G, & Strandbu, Å. (2013) Tidsskrift for Norsk Psykologiforening 2013:50.
- 16.Sykepleien 2/2013
- 17.IS-1798: Utviklingsstrategi for helsestasjons- og skolehelsetjenesten, Norwegian Directorate of Health 2010.
- 18.Heggland, Gärtner og Mykletun, Kommunepsykologisatsingen i Norge i et

- folkehelseperspektiv. report 2013:2, Oslo, Norwegian Institute of Public Health
- 19.Folkehelseinstituttet, 19.11.13 http://bit.ly/1cEQEhC
- 20.UN Committee on the Rights of the Child General Comment No. 15(2013) CRC/C/GC/15
- 21.Norwegian Board of Health Supervision, IK-2621:Helsefremmende og forebyggende arbeid for barn og unge 0-20 år i helsestasjons- og skolehelsetjeneste.
- 22. The Center for Child and Adolescent Mental Health, Eastern and Southern Norway (RBUP) and The Regional center on violence, traumatic stress and suicide prevention, Region Mid-Norway (RVTS)
- 23.UN Committee on the Rights of the Child General Comment no. 12,2009 para 104, CRC/C/GC/12
- 24.Read more about the Hospital experts: barneombudet. no/for-voksne/vare-publikasjoner/sykehusekspertene/
- 25. The Patients' Rights Act of 2. July 1999 No. 63 chapter. 6
- 26.The Patients' Rights Act of 2. July 1999 No. 63 §6-2
- 27. Regulation on Children Staying in Health Institutions §12
- 28. Children born before the 37th week of fullterm pregnancy
- 29.UN Committee on the Rights of the Child General Comment no.7 (2005) Children's rights i early childhood, CRC/C/GC/7
- 30.KMC is defined as "Early, prolonged and continues skinto skin contact between a mother and her newborn low birthweight infant (<2500g, viz preterm or low birth weight infant) both in hospital and after early discharge with (ideally) exclusive breastfeeding and proper follow-up" (Cattaneo, Davanzo, Uxa & Tamburlini, 1998, Recommendations for the implementation of kangaroo mother care for low birthweight infants. Acta paediatrica, 84(4), 440-445.
- 31.Condo-Agudelo, Diaz-Russello & Belizana (2003) Kangaroo mother care to reduce morbidity and mortality in low birthweight infants. Cochrane Database Syst Rev, 2(2)
- 32Blomquist, Rubertsson, Kylberg, Jøreskog & Nyquist (2011) Kangaroo Mother Care helps fathers of preterm infants gain confidence in paternal role. Journal of Advanced Nursing.
- 33.For more information visit the chapter on "The Legal framwork around childre's health" 34.Rambøll *Helsetilbud til ungdom og unge voksne*, Report IS-2044, The Norwegian Directorate of Health December 2012

- 35. Regulation on Children Staying in Health Institutions §4
- 36. "Skole der du er. En utredning om videregående skoletilbud for pasienter på helseinstitutsjon", report from The Norwegian Association of Youth with Disabilities 2013
- 37. The Patients' Rights Act of 2. July 1999 No. 63 §4-4
- 38.Rambøll *Helsetilbud til ungdom og unge voksne*, Report IS-2044, The Norwegian Directorate of Health December 2012
- 39.UN Committee on the Rights of the Child General Comment no. 15 CRC/C/GC/15"to adopt child-sensitive health approaches throughout different periods of childhood such as ...(c) adolescentfriendly health services which require health practioners and facilities to be welcoming and sensitive to adolescents, to respect confidentiality and to deliver services that are acceptable to adolescents" (para 52.)
- 40.Link to WHO's website on adolescent health: www.who. int/topics/adolescent\_health/en/
- 41.UNs Committee on the Rights of the Child General Comment nr. 15, CRC/C/GC/15
- 42. Turn to chapter "Meetings with children"
- 43.Felitti, J. Vincent m.fl. Relationship of Childhood Abuse and Household Dysfunction to Many of the Leading Causes if Death in Adults The Adverse Childhood Experiences (ACE) Study in: American Journal of Preventive Medicine 1998; 14 (4)
- 44. White paper. Meld. St. nr. 15 (2012-2013) Forebygging og bekjempelse av vold i nære relasjoner Ministry of Children, Equality and Social Inclusion
- 45.For more information: www.statensbarnehus.no
- 46.Health personnell acts as experts and can, without being bound by confidentiality, give information to police or child welfare services obtained during a medical examination.
- 47.Stefansen, Gundersen og Bakketeig Barnehusevalueringen 2012, Delrapport 2 NOVA Rapport 9/2012, s. 8
- 48.Myhre, Mia, Lindboe & Dyb Oppdager sykehusene barnemishandling? En kartlegging av utredningspraksis, NKVTS 2010
- 49.Manual from NKVTS: www.nkvts.no/aktuelt/sider/

hvordan\_avdekke\_vold\_mot\_barn.aspx 50.Piene (2002) translated and referred to: http://www.nkvts.no/tema/sider/

behandlingavbarnutsattforvoldellerseksuelleovergrep.aspx

- 51.UN Committee on the Rights of the Child General Comment no. 15, para 15, CRC/C/GC/15
- 52.UN Committee on the Rights of the Child General Comment no. 15, para 15, CRC/C/GC/15
- 53.UN Committee on the Rights of the Child General Comment nr. 15 CRC/C/GC/15 para. 28 & 29
- 54.NOU 2011:10 I velferdsstatens venterom
- 55.The Norwegian Directorate of Immigration annual report 2012: http://www.udi.no/globalassets/global/aarsrapporter\_i/aarsrapport-2012.pdf
- 56.The Norwegian Directorate of Immigration statistics 31.10.2013
- 57.Lidén m.fl. Medfølgende barn i asylmottak i NOU 2011:10 I velferdsstatens venterom
- 58.A summary of research can be found in Paidos (The Norwegian Paediatric Association member magazine) from 2012: Paidos 2013;30(2):53-100.Research from Denmark conducted by Edith Montgomery (2011), indicates that the conditions at reception centers and the insecurity surrounding asylum seekers can affect their future mental health. Research conducted by Hilde Lidén, Marie Louise Seeberg and Ada Engebrigtsen gives information about the life of accompanying children of asylum seekers. There is also an extensive review of the literature available from the Scandinavian countries over the past ten years. There has been quite a lot of research on children in reception centers, however, there has not been reported any significant findings on any correlation between long term stays in reception centres and mental health.
- 59.Nielsen, S.S.M Norredam, K.L Christiansen, C. Obel, J. Hilde og A. Krasnik (2008). Mental health among children seeking asylum in Denmark the effect of lenght of stay and number of relocations: a cross-sectional study. BMC Public Health 2008, 8:293.
- 60. Brekke, J-P: While we are waiting. Uncertainty and empowerment among asylum-seekers in Sweden. Oslo, Institutt for Samfunnsforskning, 2004.
- 61.Letter from RVTS Øst to The Ombudsman for Children dated 28.06.2013 & letter from RVTS Nord to The Ombudsman for Children dated 26.06.2013

