

Speak up! Giving a voice to Europe's most vulnerable children

About the rights of deaf and hard-of-hearing children in Sweden

Speak up! Giving a voice to Europe's most vulnerable children will focus on children aged 12–15 years belonging to particularly vulnerable groups in eight European countries. There are children from the travelling community (travellers), Roma children, children with disabilities, children living in poor urban neighbourhoods, unaccompanied refugee children, refugee children, and children taken into care. These are categories of children whose rights are often violated and whose voices are less likely to be heard. The study will also include children from regular groups from the same eight countries: Bulgaria, Greece, Hungary, Ireland, the Netherlands, Poland, Sweden, and the UK.

The study is coordinated by researchers from Eurochild's thematic working group 'child participation' and the Education Foundation. The project aims to address a gap in our knowledge and understanding of children's own views of their rights, the protection of those rights, and their opinions on necessary national and European policy actions. It will target children who are particularly vulnerable due to their situation or characteristics. Focus groups with creative elements will be conducted together with the kids for a few days. The study will also provide a methodological contribution to the knowledge of how children's participation can be increased. Experiences in different countries and among different groups will vary enormously (children in prison, children with disabilities, migrant children etc.), so in several ways it will not be possible to make real comparisons between special groups and countries. Instead, there will be a description of how involvement (participation) is perceived in different countries by the children who themselves belong to vulnerable groups, but also the children from the same countries belonging to a regular group.

THE AIM OF THE STUDY

The project aims to empower children and increase our knowledge and understanding of children's own views about their rights, the protection conferred by these rights, and their perception of what needs to be improved in national and European policies.

The project has **four main objectives**:

- to empower children in circumstances or with characteristics that make them particularly vulnerable, by demonstrating how these children can be heard and how their voices can be taken seriously
- to ensure that the views of children are heard by policy makers, by passing on children's
 messages to EU leaders (as well as national policy makers) and in particular by providing input
 to the development of the EU Strategy on the Rights of the Child and to the EU's work on
 tackling child poverty and social inclusion.
- to improve the practice and support the development of a culture of children's participation, by developing tools for children's participation methodologies, in particular vulnerable groups of children.



• to strengthen mutual learning across EU Member States and the exchange between children and organizations, by providing an opportunity to exchange views on children's experiences and how children's voices are heard elsewhere in Europe.

SWEDEN

Participants in Sweden

The Swedish part of the study included a group of children with disabilities – hard-of-hearing and deaf children 14–15 years of age. The students that took part in the conference were 4 boys and 5 girls. They all knew sign language, but some also used spoken Swedish and preferred to talk. All the children in this group attended a special school for deaf and hard-of-hearing children. All but one of the students has hearing parents. One has a sister or brother that is hard-of-hearing.

Another part of the study is conducted with a group of children from regular schools. They are 15-19 years old and later another part of the study maybe will be conducted.

Project leaders and language

Four project leaders, one deaf, one hard-of-hearing, and two hearing worked with the children at all times. One of the leaders used sign language, one used Swedish, and two were bilingual and functioned as interpreters. We had to communicate in sign language and spoken language at the same time.

The program

We worked in a conference with a group of deaf and hard-of-hearing children (n=9) for two days in consultation focus groups. A further half-day will later be spent to provide children with feedback from the study. The first two days, when the empirical data was collected, took place at a conference centre about 15 km from the special school that all the students attended. The students and the leaders spent the night in the same building at the centre.

On the first day, the students received information about the program, Speak up!, and a brief overview of the UN Convention on the Rights of the Child (UNCRC). We also discussed the following questions: What do we mean by the concept child? What is discrimination? Do children with a hearing disability have the same value as hearing children?

We played the Children's Rights game, which has been translated into Swedish and was visually translated into sign language. The game has a deck of cards with articles of the convention on them. The next activity involved small groups of three students each choosing four of the UNCRC articles that they considered the most important for them personally. In the afternoon we held creative workshops using photographs, drawings, theatre, or other methods of expression to illustrate the chosen articles. During the course of this day we performed several energizing activities (see appendix 2).



On day two, we began the consultation with PI-interviews on children's rights. The students were asked to apply the UNCRC to the situation of deaf and hard-of-hearing children. They were asked to give examples of both good and bad things about being a deaf or hard-of-hearing child. The next task to complete was a panel discussion, and finally we performed an evaluation of the two days.

Methodology

Focus groups are used as a method to obtain the views of the children about their awareness of their rights, experiences of the protection of rights, and their opinions on policies relevant to them at the national and European level. In the focus groups, the game of children's rights, face-to-face Plinterviews, panel discussions, and creative activities will be used. The work within the project will educate the students about children's rights and attempt to empower the children included in the study.

The term focus group refers to several individuals being interviewed about a subject at the same time, usually by two interviewers. In this focus group, or consultation process as we also call it, there were four interviewers so that the language competence would be high. In focus groups, discussion is organized to explore individuals' perceptions and experiences of a particular theme (Kitzinger, 1994; Tinnfält, 2007). Focus groups have been used since the 1920s in studies of attitudes and perceptions with adults as well as children (McLafferty, 2004; Walden, 2006; Brunnberg, 2010).

Consultation focus groups with the children

We began the conference where the consultation focus groups with the children took place by playing a game in which we all introduced ourselves to each other. The young people and project leaders participated on equal terms. We interviewed each other in pairs about our personal character, shoe size, what leisure activities we enjoy, what kinds of animals we like, and what three things we would take to a desert island. The interviewers then introduced the interviewees to the others.

The young people were also informed about what the program for the two days would look like, and we explained that our work simply concerns how the Convention on the Rights of the Child (CRC) relates to the young people's situation. There is a time plan, but it can be influenced by wishes that emerge and how long various parts of the program take. We begin by asking if they know what the UN is. The children answer that it is an abbreviation for the United Nations. One student believes the CRC is a meeting place for different countries to decide on shared global conditions. Its main purpose is to bring about peace on earth. Another student believes the CRC is meant to rescue children from natural disasters and poverty, another says that the CRC is about children's rights in society. A third student says that the CRC is a list of things that countries must agree upon. At the outset of the consultation, the young people had only a very vague idea of the contents of the UNCRC.

Who are children?

All students were asked about the difference between the concepts of child, youth, and adult. One of the young people says that youth begins when you are 13 years of age, when you begin to take on more responsibility. Another says that one's youth lasts until 25 years of age, and one's teens from 13 to 18 years. A third says that a teenager is the same as a youth. A fourth that youth is when one is between 15 and 19 years of age. Children are between 0 and 10 years old, says one. Another says you are a



child when you are under 18 years of age, while one's parents make decisions on one's behalf. A student tries to sort things out saying you are a child when you are under 18, but a youth from 13 to 19 years of age, more or less, even if you are a child at the same time.

It was not easy to clarify the difference between children and youth. We tell them that in the UNCRC children are defined as all persons up to 18 years of age. In daily speech one can use the concepts in different ways, and that the concepts of children and youth can overlap and be used differently in different contexts, as this discussion showed.

One of the young people continues to try to sort it out, but from an adult perspective. The student says that an adult is a person experience that they removed a priority who is 18 years or older. The same person says, on the other hand, that you yourself have to decide when you feel grown up. The student believes that there is only one sequence: child–youth–adult. The juvenile stage is between childhood and adulthood. When you turn 18 you receive more responsibility; you are entitled to vote, you become of experience that they removed a priority to your own place, and you can go to the pub. On the issue whether children and adults have the same rights, one student answers that they have the same value. Another student says that adults have the right to drink alcohol while children do not – therefore they have different rights. The students then get into a discussion about why children should not drink alcohol and agree that it is for health reasons. And they continue by further discussing what happens when you do not have any parents, which leads the discussion into foster care and mentoring.

To the question 'What are you? Are you children?' one of the student's replies that they are not children, but that they are young. 'Well, according to the UNCRC, we are children,' says another. Once they understand the meaning of the UNCRC we leave the question aside and tell them that we will mostly call them young people, as this will be the most comfortable concept for them, but that they also can be described as children in line with UNCRC or students.

What is discrimination

Adults, young people, and children all can be discriminated against, stated the deaf and hard-of-hearing young people. They have all experienced discrimination although one of the main articles in UNCRC states that all children are equal (Article 2).





All children have equal value (translation of the text in the picture)

During the session, the students discuss the concept of discrimination; one says that it comprises abuse, bullying, assault, or kidnapping. You may also be discriminated because of your colour, how you look or behave, your religion, or your disability. Students say they have suffered discrimination because of their disability, e.g. being told he/she may not ride the bus because of the driver's decision. Another student says he or she feels excluded when people do not realize that he or she is hearing impaired. Students discuss whose responsibility it is to inform others of their disability; for instance when you feel left out you can say that you have a hearing disability and that others must speak clearly, visibly, and directly. Such situations can occur at family gatherings, says the student, who is the only one in the family with a severe hearing impairment. The others in the family are hearing. Young people and the deaf/ hard-of-hearing project leaders also give more examples of discrimination that they themselves have experienced. We will return to this topic later in the text with more examples, but also provide suggestions for how to solve problems of more systematic discrimination.



The main articles of the UNCRC

We began this session by using a children's rights game with a deck of cards with the rights of children. In this children's rights game, the most important rights in the Convention have taken on the form of traffic signs. Fourteen traffic signs are about real rights of children and eleven are fake rights. The young people were asked to decide which ones were real rights and which were fake. They were able to quickly agree on this and gave quite accurate evaluations. The group was then split into three smaller groups of three young people each. They were asked to select four articles of the UNCRC which they viewed as the most important ones for them.

The different young people gave a fairly consistent message about which articles of the UNCRC that they thought were important in their lives. All three groups agreed on two of the articles as being most important. There was more division about other priorities, but they were in agreement that all the articles they chose were very important

All children have a right to health care (Article 24)

The child's right to health care is an important right that all the young people agreed to select as highest priority, and one of the key articles of the UNCRC.





But there was also a negative side behind the choices they made, which they also reported in the following discussion. They could, because of their communicative disability, experience experience that they removed a priority. This is a violation of Article 2, which states that no child should be discriminated by being treated less favourably than others. It could happen that deaf and hard-of-hearing young people were prioritized less than others in actual situations where they sought medical care. This might be done by health care professionals who did not know sign language or did not want to try to communicate with them. Some of the young people also reported that adults received care more quickly than children.

This can be interpreted as discrimination in health care, and the deaf and hard-of-hearing adolescents may therefore face double discrimination. This may be a systematic form of discrimination based on their difficulties communicating solely with spoken Swedish. In emergency situations this is very serious. It can be improved if staffs are aware of and can make use of modern technology. Telephone interpretation ought to be possible, and would increase the security of the assessments but also increase the sense of availability, competence, and a gracious welcome.

A somewhat different problem is that adults receive treatment more quickly at the clinic than youth who have to wait longer. This is a generation-related problem and might be a violation of Articles 2 and 24 if it not is a medical decision about the need of help. The young people studied often seek medical care on their own. That their parents do not accompany them and provide assistance may be due to the fact that young people with severe hearing loss leave home earlier than many hearing children in order to go to special schools. These special schools are often in a different city than where the student's parents reside. The young people live in the school's housing, a weekly family home, or a residence of their own.



Alcohol, cigarettes, and drugs kill.

Never test! Then you try them! Otherwise you'll get addicted (translation of the text in the picture)



I painted this picture because I have seen many kids in my school who drink and smoke. I think they should stop doing this because I have seen many of my friends are injured, suffer from anxiety, and develop problems with brain damage. So I want to stop drugs, cigarettes, and alcohol among children which is why I painted this and wrote that you can die from it. If you try them, you risk becoming addicted (comment from the creator of the picture).

Research studies have also shown that deaf and hard-of-hearing youth use more sedatives than hearing youth, or use alcohol for what is perceived as purposes of self-medication. This may be due to poor communication between medical personnel and the young people, rather than the young people functioning less well psychologically. It may also mean that they feel worse and are exposed to discrimination, and do not receive the help they need. There may also be other interpretations. There is a need for more background knowledge about deaf and hard-of-hearing youth's use of sedatives, alcohol, and drugs. It may be a negative spiral that can only be broken if medical personnel develop better communicative skills so as not to prescribe sedatives when the situation is complex and stressful because they are communicating in what may be both parties' second language, and it is therefore difficult to evaluate the best interests of the child. For the deaf and hard-of-hearing youth, availability and access to health care for all is very important and is something that pleases them when it exists.

All children have the right to education (Article 28, 29)

The right to education is important and contentious issue for the deaf and hard-of-hearing children. All students participating in this study attend special schools, but several of them also have experience from the regular school. One view shared by all and that one of the students expressed was that 'All deaf and hard-of-hearing are entitled to receive education in their language. Everyone has the right to use sign language'.



When I go into a class (translation of the text in the picture)

One of the drawings illustrates what a classroom in the special school can look like. Classes are small. As the picture shows, there can be six students in a class, more or less. The students are placed in a semicircle making it easy for them to see each other and make eye-contact, which facilitates communication in the classroom. The furnishings are also adapted to facilitate communication in other respects.



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The hearing school environment

Some of the students have previously attended a school with a majority of hearing students. One of the students tells how he/she felt lonely and excluded there. The student felt more shame about his/her disability than in the special school. It could be both difficult and easy to get help in the regular school environment where the majority of the children could hear. The student describes the situation as follows: 'many people don't think about [the importance of] speaking clearly.' Good communication requires eye-contact, which makes lip-reading possible, according to the same student. Another describes how difficult it is to hear when people speak behind your back and you cannot see their lips. A third student tells that it was difficult to follow what was going on in stressful situations. It is easier to keep up when the tempo is calm. Another student agrees, saying that it is difficult to keep up when people speak quickly and forget to adjust their speech. Sometimes you get into situations where you feel awkward and do not know what you should do because you are completely unable to follow what is going on around you. These students have thus been forced to switch from regular schools to the special school in order to improve their school situation.

In a special school – A sign-language environment

The learning environment at the special school is not entirely without its problems either. One student describes feeling discriminated when conflicts arise between teachers and students, because the students feel they are worth less than the teachers. The student thinks the teachers should listen to the students more. Another student is annoyed that some teachers have incomplete knowledge of sign language, making the communication less smooth between teachers and students. When the teacher says 'huh?' several times the student finally tires and gives up. Another student agrees, saying that they have to sign extremely clearly to one of the teachers, which is a hassle. The dream would be for all the teachers to be fully proficient in sign language.

A school for all?

The students were asked what they thought of the politicians' ambition to integrate everyone into the same school system. One of the students was divided; that is, it would be fun because there are so few deaf and hard-of-hearing students, and an integrated school would offer more friends to choose from. The discussion leader clarifies that it would mean that all deaf and hard-of-hearing students would attend school in their home municipality in the same classes as hearing students. When the students realized that this means they might be completely alone in their class and in a hearing school, none of them wanted it to be that way. One student wishes that all the deaf schools in Sweden could be combined into one large school for the deaf. Another thinks that the deaf school that they attend could be accommodated in a hearing school, so that the deaf and hard-of-hearing students would just have their own section – just like at the national upper-secondary school for the deaf today. The hearing students at such a school would have an opportunity to learn sign language, according to one student. They want a school that puts the language at the centre – sign language – rather than the disability –



just as at Kattungen's pre-school today (see Brunnberg & Fredriksson, 2007; Kattungens förskola, 2012).

This could suggest that the students are expressing a desire to attend a larger school and have greater contact with hearing children, not however that it should happen on an individual basis. They do not want to be the only deaf or hard-of-hearing person in a class or at a school for hearing students. What the young people seem to be advocating is a form of reverse integration similar to that in the sign-language environment located adjacent to the special school that the students attend. The sign-language pre-school environment Kattungen (Kitten) is also attended by many hearing children. The hearing children have some connection with sign-language and possess age-suitable signing skills because they, for instance, have deaf or hard-of-hearing parents, siblings, or relatives who also communicate in sign language. When hearing children reach school age they have to attend a school for hearing children. They cannot continue at the special school, which is the sign-language environment for schoolchildren.

The coming articles had been prioritized differently by the students in the consultation focus groups, but they all considered them very important.

Ohildren with disabilities are entitled to special care (Article 23)

The students describe themselves as having a disability but emphasize that it is not severe; it's 'just that we can't hear.' The problems are more related to the environment.

To have a disability is not the same as being ill but you can need medical treatment, assistance or means.

We children with disabilities have a right to medical treatment and care (excerpt from discussion among youth).

In their pictures, two young people have chosen to illustrate the importance of this article for young people's situation if they have a disability. This can suggest that it is easier to describe the situation to others than oneself, but also that being deaf or hard-of-hearing means having an invisible disability, while physical disabilities are more visible and therefore are easier to illustrate when describing the need for assistance and barriers in a picture.





I think every child in a wheelchair do not have good roads and things for them (comment from the creator of the picture).



People who use a wheelchair have difficulty getting up stairs without a ramp, or are not able to or want to take the elevator as they perhaps are afraid to risk getting stuck in. That is why I have designed this ramp because they do not have to be afraid and it will be easier for people to get up (comment from the creator of the picture).



Children have the right to receive the medical care they need from the health service. For us deaf and hard-of-hearing persons, health care means receiving hearing aids or ear examinations. But that does not feel like health care, says one student. This student shows that disability and illness can be two different conditions. A person with a disability may feel healthy, despite needing assistance or technical aids.

Children have the right to express their opinion and children have the right to information (Artikel 12 och 17)

The deaf and hard-of-hearing young people discussed that all Children have the right to express their view but they had more opinions about children's right to information. They discussed situations of enclosure and the stress about not knowing and to become out of information in acute or risky situations or when something had been changed.

Everyone is entitled to receive information, such as the subway or on the train, we deaf and hard-of-hearing have the right to get information just like any other (excerpt from discussion among youth).

The young people said that they have a right to know what to do in an emergency, for example if the train they are going to take suddenly arrives on a different platform. It is a problem being deaf or hard-of-hearing because

...they can't hear what is announced over the loudspeakers on buses or trains (green note)

This even applies to many hearing people. Another situation is when special information is given on the train, which is often done over the loudspeakers. Deaf or hard-of-hearing passengers miss this information. One solution could be to provide more information on the text displays on the trains, says one student. Another thinks that there could be direct translation via video phone link on occasions when special information is provided. Or why not having a display at every seat, adds another student. It would be nice not to have to take the initiative on one's own all the time. The young people hope that the state railway (SJ) and other transport companies will adopt these ideas. It is now technically feasible to provide written information and information in sign language. For deaf and hard-of-hearing persons, travelling by train is unnecessarily stressful today.





In Sweden and many other countries, extensive efforts have been made to increase accessibility and enable persons with physical disabilities to travel and take part in various activities. Accessibility also applies to communication. Access to information is crucial to one's ability to participate and have access to an activity, as well as to get around by means of public transport. It is especially important that information reach everyone in emergencies and disasters. At present, according to the young people, this does not work at all for them: instead it is stressful and limits their mobility.

A discussion leader mentions that she feels discriminated in the community because as a deaf person one cannot fully participate, mentioning the door entry intercoms that can be found here and there. Deaf people cannot use these because you need to speak with someone through the intercom. A participant thinks that it should be possible to communicate with text on the intercom systems. Another thinks it should be possible to use video phone interpretation over one's cell phone, either holding it up or connecting it to the entry system. In fact, there is a place in Örebro with video communication in the door entry system (the translation centre's intercom).

The same discussion leader mentions feeling left out when people who are not fluent in sign language omit information, for instance, in radio broadcasts. The leader feels like an outsider when she misses public service announcements.

The public transport information systems need to be modernized to improve clarity and accessibility in everyday situations as well as for reasons of emergency and disaster readiness. A modernization of information provision would benefit everyone.



Children are entitled to protection from sexual exploitation (Article 34).

The protection of sexual exploitation is very important was the opinion of all young people in the consultation group. They knew of peers, even boys, who have been victims of abuse. They also knew that the victims had been helped.

Research in the same county in Sweden show that girls and boys with disabilities, 15–16 years of age, report a significantly higher rate of sexual debut than adolescents with no disabilities (Brunnberg, Lindén Boström & Berglund, 2009). The sexual debut can be desired by the adolescent and be with a partner of choice, or it may be involuntary and occur in an abusive situation. Another study in the same county with girls and boys, 17-18 years of age, show that force at first intercourse is more common among girls with multiple disabilities or one disability, than those without a disability (Brunnberg, Lindén Boström & Berglund, in press).

PI interview

The themes that we had chosen for the PI interviews were on the one hand a hearing-impairment theme and on the other hand a participatory theme in which the young people were asked to write things that are bad about being deaf or hard-of-hearing on a green sticky note, and things that are good about it on a yellow note. The second theme involves writing on a note when the student feels involved and when he/she feels left out. They were then given the task to illustrate one of the themes with a drawing. The brief notes from the PI interviews were just a starting point for the following discussion during which both positive and negative aspects of the two coming themes were talked about.

The excerpts presented below reflect the fact that written Swedish is a second language for the deaf youth; for instance they sometimes use a different word order. Minor linguistic corrections have been made to aid understanding.

It is good to be deaf/hard-of-hearing when....

When the young people were to describe advantages of being deaf or hard-of-hearing, three mentioned the advantage of not being disturbed when they are sleeping.

When you're asleep it's nice not to have to hear everything. So if you don't want to listen you can switch off your hearing aid. (yellow note)







When you want to sleep deeply and peacefully. (yellow note)
When you're asleep you sleep extra well because you can't hear anything and, for
example, if there's thunder you don't have to hear the noise (yellow note).



Not having to worry about noises you can hear in the dark but do not know what they are turned out not to be important to everyone in the focus group. One student describes using his/her eyes more when not using his/her cochlear implant (CI)¹ and instead being able to see anything that is moving. This student says that the same worry can also be found among deaf and hard-of-hearing people when surrounded by darkness. The focus group discussion further explored the question of advantages and disadvantages about being deaf/hard-of-hearing. It found that there is such a thing as visual noise. The deaf and hard-of-hearing can sometimes be disturbed by different things than hearing persons. For example, the students are disturbed by things that are moving, or by people waving their hands about. Another example of things that can interfere with understanding communication is a person's choice of clothing. If people are wearing much patterned clothes it can interfere if you need to look at them for a long time while they talk. This is the reason why sign-language interpreters always wear dark, single-coloured clothing when working.

Another disturbance is tinnitus. 'Sometimes it's hard having tinnitus', says one student, when there are sounds in your head that you cannot get rid of. 'Sometimes you don't know if you're imagining the sound or if there are real sounds outside.' 'The tinnitus starts if there's loud noise around you' says one student, while for another it comes 'when everything around you is quiet.' A third student describes often having tinnitus at night. One student mentions getting tinnitus when reminded about it, such as right now. Five out of nine persons in the student group have tinnitus, so the benefit for the deaf of experiencing silence does not really exist for them.

Research has shown that hard-of-hearing youth often suffer from tinnitus. There is a significant difference between the incidence of tinnitus among hearing-impaired (39%) and hearing (6%) youth (Brunnberg, Lindén Boström & Berglund, 2008). The hearing-impaired more often suffer from tinnitus as a group, but there is also a gender difference, with more hearing-impaired boys (50%) than girls (28%) suffering symptoms. A corresponding gender-related difference has not been reported among hearing youth.

Another advantage of being deaf or hard-of-hearing mentioned by two of the students is that you can decide for yourself if you want to listen to someone. You have the possibility to choose what you wish to hear within the area that you can hear. A further advantage is being able to communicate with a friend by sign language, which most hearing people do not understand.

... if you want to talk about something with a deaf friend, hearing people can't understand us. (yellow note)

In other words, one can keep things secret. Another advantage that sometimes exists is that you can avoid being exposed to things that are negative; 'you're blissfully unaware of a lot of crap', according to one student.

... Deaf: not having to hear bullshit. Hard-of-hearing: you can hear well! (yellow note)

However sadness and vulnerability also emerge in the quotes and the discussion. It is bad to be deaf/hard-of-hearing when...

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¹ Surgically implanted electronic device that provides a sense of sound to the person.



...you can't keep up with what others are saying. (green note)

When I ask hearing people about something and they say what? Huh? Are you nuts? (green note)

For the deaf, meeting with disparaging reactions when trying to communicate with hearing peers is painful. On the drawing, a comment underlined in red says that deaf people are NOT STUPID.

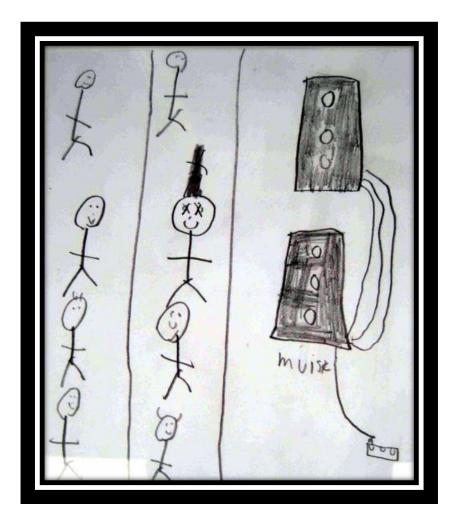


The deaf children just want to communicate with the hearing children Deaf are not stupid (translation of the text in the picture).

Another thing that emerges in the PI-notes and the discussions is a longing to be able to take part in activities that are important to many hearing youth.

- ...when you want to go to a concert/play (green note)
- ... and deaf people cannot listen to music or talk and hear (green note)





Music

Another enjoyable activity that is far from unproblematic is going to the public swimming pool. Previous research has found that many hearing-impaired people cannot swim, which can lead to a serious situation arising (Brunnberg, Lindén Boström & Persson, 2009). It can be difficult to take part in swimming lessons at the pool because 'you can't use your hearing aid or cochlear implant and can't follow along as well – IF you're there with hearing people, that is.'

... if I go to G-vik [an adventure pool in Örebro] or go swimming I can hardly hear what they're talking about. (green note)

Another problem mentioned by one of the young people is the difficulty of noticing if someone else needs help.

...when you're swimming if someone needs help and is screaming. (green note)

Social situations and situations of danger, including the possibility to be the one who helps others, can accordingly be negatively affected by hearing loss.



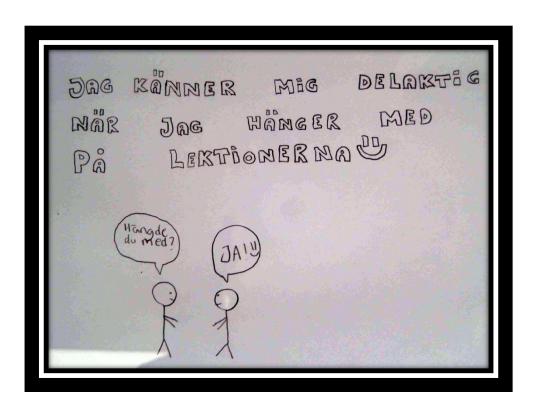
Participation and Exclusion

Most of the young people mention school in different ways when making brief statements about positive inclusion. The school environment is only occasionally brought up by students when describing situations where they feel excluded.

🤰 I feel like a participant when ...

I'm in class (yellow note)
I was in school (yellow note)
I'm doing something I'm good at (yellow note)
+ during gym, at home with my mum, in the dormitory, in school, friend (yellow note)
I'm with my friends. When the teachers talk about something interesting (yellow note)

The quotes from the young people show that participation in school can comprise several different aspects. It can include social participation or scholastic participation. Feeling included in school, according to one student, involves being able to be together with friends, but also being able to keep up in class. The same student had previously attended a hearing school, but did not feel included because he/she could not keep up. The same student feels like a participant in his/her current school because he/she can feel similar to and identify with the others. Thus social participation also has a psychological dimension.



I feel participation when I do understand the lessons (translation of the text in the picture)

Another student describes participation during class as understanding what the teacher is saying and being able to follow what the other students say. The teacher's attitude is important, according to a



further student, who likes his/her crazy gym teacher. Yet another student says that a good lesson is one in which all the students actively take part. Another student adds to this, saying it is important that the teacher is active, that the teacher has good teaching skills. One student enjoys Swedish class because the students receive clear and well-organized information in sign-language as well as in spoken and written form. The same student dislikes teachers who have favourites among the students, and another student agrees.

A good class is one in which all the students take active part, when the teacher is active and does not favour one student, but helps others and listens. It is also good when the teacher teaches well and provides clear written and spoken information, and when everyone can sign with each other.

A youth study was conducted by a research circle consisting of young people about the concept of participation in school. The group who carried out the study were somewhat older, 15–19 years of age, in the same city. The research circle and the youth study included young people from both regular schools and the special school (see Åkerström et al., 2010; Åkerström and Brunnberg, in press). In this study, which was designed by adolescents, several dimensions of participation were reported on. One could be called *participation in decision-making*. Student government, lunch committees, and class committees gave students influence and enabled their voices to be heard. This type of participation was not mentioned by the students in this study. In the study of adolescents, in which 100 young people some of whom were the same age as those in the current study - responded to a questionnaire, social participation, or spending time with friends, was an important part of participating in school life. Social participation is mentioned as an important form of participation by the young people in this study as well. A third type of participation in school life was called by the young researchers *participation in learning*. They described this type of participation as wanting to learn, being motivated, and feeling enthusiasm about what is being taught. They emphasized that both students and teachers were responsible for creating a good collaboration. The students in the current study also describe participation in learning as being of central importance. It is important to understand what the teacher is saying, but also that both the students and the teacher are active. A fourth and central type of participation that the young research partners emphasized in their report involved being included in a linguistic context, that is, communicative participation. This is described in the youth study in terms of the importance of knowing what friends and teachers say, but was not primarily about being able to hear or not.

Hearing students also described feelings of exclusion when the teacher used words they did not understand or when friends talked about something they were not aware of. (Åkerström et al., 2010, p.17)

In the present study, communicative participation is of the utmost importance. This can concern verbal comprehension, but is also described by the young people in the present study in a similar way as in Åkerström et al.'s study (2010). Inadequate participation is described as

...friends laughing without me (green note)

When friends are laughing and I don't know what they're laughing at, then I feel left out', says one student. Another agrees, saying that it's easy to think that they are laughing at you, when you do not know what they are laughing about.





What can I say? I need help. All kids have a right to... something... (comment from the creator of the picture)

School is an important arena for interaction and participation, but there are also others, as one of the young people describes in the following list,

at gym, at home with mum, the dormitory, in school, friend (yellow note)

Gym can be in the school or a leisure time activity. At home with mum or in the dormitory reflects the special situation of many deaf and h students who live away from their parents. The parents too may live separately. Relatives can also make up an arena of belonging or lack of belonging. Friends can be peers they spend time with in school and in their free time, but can also be friends who do not attend the same school. Participation or a lack of participation can thus be found in many arenas, but also situations where there is a strong desire for freedom.

I can go to the parents-free party. (yellow note)

Another way of feeling included can be to be allowed to go to party without parents present – where you are with friends. 'Parents don't need to know everything', says one student. Another agrees, saying that parents do not need to decide about everything. Peers, along with social participation, are important both in and outside school.

I have someone to talk to, and have fun going out with friends. (yellow note)



In constructing personal identity, that is to say, knowing who I am, peers in various groups are important social-interaction partners (see Brunnberg, 2010).

I hang out with those friends who talk .(yellow note)

In the task to describe the feeling of being excluded, it was primarily in relation to friends or their own families that students in this study described exclusion. Only one of the students described being excluded in school.

Sometimes with my friends, when I sometimes feel left out in school. (green note)

Exclusion is related to the lack of a language in common within the family. This becomes especially glaring at family get-togethers with relatives.

My family can hear and I feel left out. They don't know sign language very well. (green note)

Most often when we are at family get-togethers, or else everyone is talking so I can't understand. (green note)

All but one of the students has hearing families. One of the young people also has a hearing-impaired sibling. The students' families have varying levels of skill at sign-language. The parents of two students do not know any sign language at all, one student's parents can sign a little bit, another student's mother can sign better than his/her father, another's mother can sign, but father cannot sign at all, and another's father can sign better than his/her mother. The parents of two students can sign rather well, though not fluently. Another student's parents are deaf themselves.

When it comes to whether students' parents are deaf or hard-of-hearing, the distribution is normal. Thus the parents must learn a new language to be able to communicate with their children. In 1981, sign language was recognized by parliament as the first language of the deaf, which entitled them to dual-language status (Brunnberg, 2003). Sweden was the first country in the world to grant official status to sign language. In 1983 it was established that classes in the special school would be taught in sign language and Swedish. However it is still the case that parents have varying levels of ability in sign language and most family members know no sign language at all. Exclusion in the family and among relatives can have a linguistic and communicative basis, but may also be because they do not live together either. The quotations from the young people also indicate that often live in collective accommodations.

Being alone can be self-chosen, and in that case have a positive foundation.

Don't know. I decide for myself, and like to be alone sometimes. It's nice. (green note)

But being alone can also be sign of alienation and of lacking friends.

When I'm alone without friends. (green note)

A friend invited me to a party but I didn't get let in. (green note)





Loneliness and the feeling of being unwanted is the most terrible poverty (text in the picture)

On being 'dissed'

On one of the sticky notes describing the feeling of exclusion the following can be read:

When someone disses me. (green note)

'When someone disses me because I'm deaf or hard-of-hearing I feel excluded', says a student. An example of such a situation is when you are in an argument and cannot speak very well, and the other person disses you, according to another student. Another student was dissed on the bus by the driver for not being able to make him/herself understood. The same student described a recent incident in Stockholm in the child-minding section of a grocery store, where a child was refused admittance because it was deaf. Another student mentions the example of asking for directions to the town square and being dissed after showing that he/she cannot hear – that makes the student feel excluded.





Hearing people who talk trash about a deaf person (Comments from the creator of the picture).

Dissing is a phenomenon that closely resembles bullying. According to Wikipedia (Swedish Wiktionary 'dissa') it means to criticize, denigrate, and make disparaging comments about someone or something; to fob someone off. Bullying, according to the same dictionary, refers to one or more people being subject to systematic harassment within a social group. The difference between the two concepts seems to primarily lie in whether the disparaging comments are made systematically.

A discussion leader describes feeling dissed when people think she is strange and do not understand that she is trying to communicate. This sort of thing often happens in other cities, where knowledge about the deaf and hard-of-hearing is less widespread than in Örebro. Another student tells about hearing extra badly because the batteries were dead in his/her hearing aid; a person tried to talk to the student by putting his mouth right next to the student's ear, whereupon the student felt threatened and pushed him away. Another student agrees, saying that it is common for people to try yelling or get very close and speak, which only makes the situation worse.

PANEL DEBATE

Fictitious opening question: The government has decided that deaf and hard-of-hearing schoolchildren should be integrated into the schools in their home municipalities – in line with the concept 'one school for all' as opposed to 'education for all'. Those labelled 'integration' below are in favour of 'one school for all' and those labelled 'special school' are against the proposal. Take note that this is a role-playing game and not what the students themselves think. Also, the debate is presented in a somewhat abbreviated format. The different standpoints can take on a very absolute form in this kind of discussion. The students are wearing funny hats to indicate that this is theatre. When the hats are removed after the panel debate, they become themselves again.



Special school: Deaf and hard-of-hearing students should go to special schools, not integrated ones.

Integration: I think the proposal 'one school for all' is good because everyone is equally valuable and that means one can feel just as ordinary as everyone else if you attend school in your home municipality. Communication can take place with the help of teachers who know sign language or interpreters.

Special school: No, it's better for deaf and hard-of-hearing students to have one school, and hearing students another, because then the language and communication among the students is smoother.

Integration: Nowadays technology's been developed that we can use to improve the communication.

Special school: But technology won't enable us to communicate smoothly; it's best that everyone is in the same place.

Integration: But it's possible to teach sign language to everyone.

Special school: That's unreasonable; everyone won't learn sign language.

Integration: It would be more economical if all students attended school in their home municipality.

Special school: But everyone's at different levels and it would be impossible to give everyone the same amount of help. What's wrong with the way it is now?

Integration: The commute is a hassle for students who live far away from the special school.

Special school: But there are dormitories!

Integration: It's easy to make more friends in a larger school. There are too few people in the special schools to choose from.

Special school: But it's not about friends; it's about education! It's much harder to get educated in municipal schools if it means being taught through an interpreter. You can socialize with friends in your free time!

Integration: But you should learn to socialize in school as well, and be able to work together.

Special school: You do have friends in the special school, who are important. And you can meet up with your hearing friends in your free time.

Special school: I think groups would arise in an integrated school anyhow. The deaf and hard-of-hearing students would be drawn to each other, or else wind up being left out.

Everyone takes off their hats and are allowed to express their own opinions. The discussion leader asks what the students think about the scenario where the government's discussions become reality – that everyone should be integrated into their home municipality's schools.

All the students emphatically agree that it is a bad proposal. The reason, according to one student, is that deaf and hard-of-hearing students will be isolated, feel worthless, and be victims of bullying to a greater extent than today. One student says 'the way it is now, it works!' 'We spend time with students from the other special schools too' the same student continues. Another thinks that the students themselves should choose their form of schooling, not their parents. On the other hand the students propose a system like the Swedish National Upper Secondary School for the Deaf and Hard of Hearing, that is, that the special school should share a building with a normal school – so that the deaf and hard-of-hearing students would have their own section but still are under the same roof as hearing students. Earlier there have been student proposals concerning the type of integration between deaf, hard-of-



hearing, and hearing children that take place at the pre-school Kattungen, where children with several types of disabilities together with hard-of-hearing and deaf children are attending.

PROPOSALS FOR POLICIES OR ACTIONS FOR CHILDREN'S RIGHTS

The main articles of the UNCRC chosen by the deaf and hard-of-hearing children were

- All children have a right to health care (Article 24)
- All children have the right to education (Article 28, 29)
- Children with disabilities are entitled to special care (Article 23)
- Children have the right to express their opinion and children have the right to information (Artikel 12 och 17)
- Children are entitled to protection from sexual exploitation (Article 34).

The rights to health care and special care are important for the deaf or hard-of-hearing children. It is also important that children are entitled by adults to protection from sexual exploitation and that children have the right to express their opinion. The articles that started more of engaged discussion was the right to education and to information. The students gave several examples from their everyday life when they experienced problematic situations or discrimination.

The young people's suggestion to politicians and the directors of transport companies is that information on emergencies and schedule changes needs to be provided not only over the loudspeakers, but also as written text on displays. The public transport information systems need to be modernized to improve clarity and accessibility in everyday situations as well as for reasons of emergency and disaster readiness. A modernization of information provision would benefit everyone.

The right to education and the school environment also started an emotional discussion about discrimination, exclusion and feeling lonely. It could be difficult to communicate and get help in the regular school environment. Several of the students in the consultation focus groups have switched from regular schools to the special school in order to improve their school situation. In the special school it is better but not perfect. The dream expressed by some students would be for all the teachers to be fully proficient in sign language. The students also are expressing a desire to attend a larger school and have greater contact with hearing children. But they do not want to be the only deaf or hard-of-hearing person in a class or at a school for hearing students. What the young people seem to be advocating is a form of reverse integration with hearing children in the sign-language environment. The school environment is important and includes social participation as well as scholastic participation. A youth study was conducted in the same city by young people about participation in school and showed several dimensions of participation in school; participation in decision-making, social participation, participation in learning and communicative participation.

A good class is one in which all the students take active part, when the teacher is active and does not favour one student, but helps others and listens. It is also good when the teacher teaches well and provides clear written and spoken information, and when everyone can sign with each other.



School is an important arena for interaction and participation, but there are also others, like gym, home with parents, dormitory and friends. The children can have the feeling of exclusion even in their family because of not able to communicate in the same language.

Dissing is another phenomenon that closely resembles bullying and that all students had experienced. The deaf and hard-of-hearing students gave a lot of examples of being dissed, bullied or more systematically discriminated. One text written in one of the pictures is expressing a strong feeling 'Loneliness and the feeling of being unwanted is the most terrible poverty'. This is written with address to the politicians in Sweden and EU.



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Appendix 1

Conference, Örebro, 18-19 October 2011

The purpose of the *Speak up!* project is to fill a gap in our knowledge and understanding of children's own views about their rights and the protection of these rights, as well as their opinions on necessary national and European political measures.

The project will address children who for various reasons find themselves in situations of particular vulnerability. The children can experience violations of their rights, and their voices are not always heard.

The goal of the project is for programs and politicians in Europe to receive knowledge from the children about how they are treated in terms of rights, and how children's participation can be strengthened in practice.

18 October 2011

8:45 Departure from school

Lodgings

9:30 (approx) Snacks and information about what we will do in the coming days

10:00-11:00 Introductions game

11:00–11:15 What is Speak up! Brief explanation of the Convention on the Rights of the Child

11:15–12:00 Who is a child? What is discrimination? Do we have the same worth as hearing people?

12:00-12:45 Lunch

12:45–13:30 Children's rights game

13:30–14:00 Choose four articles

14:00–16:00 Creative workshop (create photos, drawings, theatre etc. about the articles selected) and snacks.

16:00–18:00 Give a presentation about the chosen articles for the others. Present three discussion questions about deaf and hearing-impaired children's experiences.

18:00-19:00 Supper

19:00- Activities

22:00 Lights out

19 October 2011

7:30 Wake up

8:00-8:30 Breakfast

8:30–10:00 PI interviews about children's rights. Is the UN Convention on the Rights of the Child applied in practice?

10:00-10:20 Snack break

10:20-11:45 Panel debate

11:45-12:30 Lunch

12:30-13:00 Evaluation

13:00–14:00 Summary of the contents of the consultation with the young people on the most important thing to convey to politicians in Sweden and Europe.



Appendix 2

ENERGIZERS

Energizers are activities that can be done between the different sessions and are needed to make sure the children have renewed energy each time around. Sources of energy can be physical activities or games. It is important that the children have fun doing them. Examples of energizers are presented below.

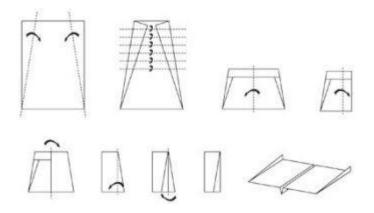
Ideas for energizers

Who can fly farthest?

All the young people are given an A-4 sheet of paper, with which they are to fold an airplane. When they are all finished with their planes and have written their names on them, a starting line is decided from which everyone throws their planes on a signal. The plane that flies the farthest wins.

Aim for the stars

Don't throw the plane straight up, but almost, as high as you can. If you can get the plane 10–15 meters up in the air, that's very good. The higher the better.



This paper airplane was inspired by the current world-record holder (Metro, 2011)

Stand on one leg

We try out different ways of standing on one leg, as well as things we can do standing on one leg. For example, whether we can bend down all the way to the floor and stand up straight again without touching the floor with our other leg.

Massage story

Everyone lines up single-file. The leader either tells a story or gives different orders for how the young people should massage each other. A story could begin like this, for example: 'I was taking a walk [pat each other's backs] and it was raining outside [makes a rain pattern]...'



The clapping game

As many as want to play sit in a circle around a table. Everyone puts their left arm under the right arm of their neighbour to the left. The hands are placed on the table, palms down. One clap of the hand shows that you move the clap in a certain direction. Two claps of the hand mean that you change directions. For example: The first person claps the table once with his/her left hand; the person whose right hand is next to the first person's left hand now claps the table with his/her right hand. The next person whose hand is to the left claps once or twice etc. If someone claps wrong, or forgets to clap, the hand in question is out. When both of someone's hands are out, he/she is out. One person after another is eliminated until only the winner remains.

Send forward

Everyone sits in a circle, without a table in the middle. A leader sets the rhythm and everyone else follows two claps on the knee and one normal clap of the hands etc. When everyone has found the rhythm the leader starts by replacing the clap of the hands with signing his or her name (in sign language, people usually have their own personal signs). Next time the hands come around (after clapping the knees twice), the leader signs someone else's name. Next time the hands come around, that persons signs still another person's name. When someone makes a mistake signing, that person is out. Alternatively, everyone can decide to be a kind of fruit, or something else, instead of signing their names.

Folding frogs

The leader begins folding a frog and has the young people do the same. Hopefully this will inspire some of the kids to make other paper figures that they can teach each other. Hopping frog

This hopping frog comes from Japan and belongs to a system of paper folding called Origami.

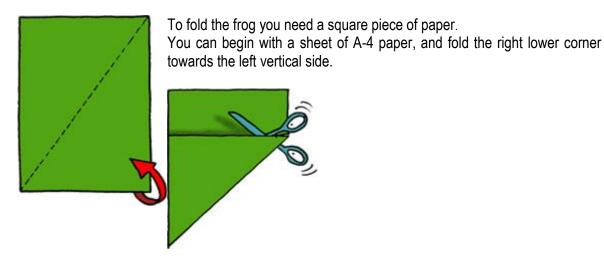


What you need:

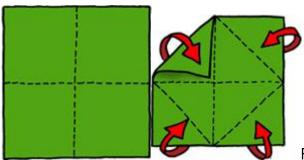
- Coloured paper (not thicker than ordinary printer paper) A-4
- Scissors
- Pens

To fold the frog you need a square piece of paper.





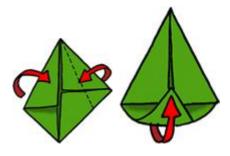
When you have folded the paper in this way, clip off the upper part. Unfold the paper again and you have a perfect square!



Fold the paper twice in each direction so that the

creases make a cross, as in the picture.

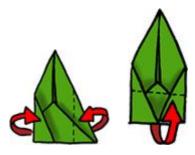
Fold the corners in toward the centre.



Fold the upper edges in so they meet in the middle.

Now you have a lower part that sticks out; fold up the upper part to make a triangle.





Fold the triangle's two lower parts in so that their points meet in the centre of the triangle.

Fold up the lower part to the middle of the paper.



Fold it back to the lower edge of the part you just folded up.



Fold down the top in the same way.

Place the frog with the folded parts facing down.



Put your index finger on the frog's 'bottom', push down and pull your index finger toward you and the frog will hop away.

Try using different coloured paper and decorate the frog as nicely as we have done.

Now you can have hopping races with paper frogs

(Instructions taken from Unga Fakta, 2011)



EVALUATION OF THE FOCUS GROUP MEETINGS

In evaluating the consultation process, the children were given the opportunity to tell the facilitators about how they felt about the consultation process by moving around in the room.

- 1. I feel that the others have listened to me when I talked. All stand on grade 5.
- 2. I think the adults have listened to me when I talked. All stand on grade 5
- 3. I think that the supervisor has been good. All stand on grade 5.
- 4. What about accommodation? Some remains of grade 5, one sits down at the grade 3 and says that the TV did not work so well.
- How has the approach worked? Most people are seated at the grade 3 and explains that the sessions were too long and for short breaks in between. The energy is diminished.
- 6. The group size, nine students, it was just right? Opinions vary, some seated at the ratings 1, some at 5. Those who were low score would like to have more students in the group so that it could be more public in such debate panel. Those who were good score like that nine people are a moderate group size.
- 7. Are you age well for this task? Some are seated at the lower grades and think it should also be offered to older students for this type of task. Another student says that age is not important but more of the students attending. Other students are seated at the higher grades, saying it was okay.
- 8. Have all been able to participate on equal terms? Most people are seated at grade 3, one student explains that it was neither good nor bad.
- 9. All stands at grade 5
- 10. Has the mood of the group have been good? All stays at grade 5.
- 11. Has the good mood helped you to have a good partnership? All stays at grade 5.