H@ssles and Hopes on the Internet: What Professionals Have Encountered in Dealing with Internet Use and Sexuality among Youths with Intellectual Disabilities

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Abstract

This study aims to provide more in-depth knowledge about professionals' views regarding Internet use among youths with intellectual disability (ID). How do the professionals describe the abilities of the youths with ID when using the Internet for social, romantic, and sexual reasons? What kinds of experiences do the professionals have of these youths' Internet usage, and how do they talk about their ways of dealing with this? In what ways do the professionals describe their own competence regarding Internet usage among youths with ID aged 16-21 years, and do they express the need for any specific tools? Qualitative research interviews were conducted with 17 professionals, 4 males and 13 females, between the ages of 29 and 58. The professionals described challenges with the youths' various emotional and intellectual abilities, as well as their technical knowledge in relation to Internet use. The results highlight three themes: A two-fold usage, Between being controlling and permissive, and A lack of strategies. The article discusses the development of a 'Participation-script', where a continuous dialogue with the youths with ID exists parallel to a restrictive Net-script. We argue that everyday school situations concern joint decision-making between professionals and pupils with ID. Such an approach to participation is based on relationships, that is, oriented towards the self-understanding and individual agency of youths with ID, as well as to the self-understanding of the professionals involved in the lives of youths with ID.

Keywords: Special Schools, Youths with intellectual Disability, Internet-usage, Participation

Background

Knowledge of professionals' experiences with Internet usage among youths with intellectual disabilities (ID) is limited, even though research shows that it is an integrated part of social life for this group of young people, as well as for others (Chadwick, Wesson and Fullwood, 2013; Löfgren-Mårtenson, 2005; 2008, Molin, Sorbring and Löfgren-Mårtenson, 2017). Many people with ID live sheltered and socially isolated lives (McVilly et al 2006), and the Internet can then be an important arena for seeking and maintaining contact with new friends and potential partners (Molin, Sorbring and Löfgren-Mårtenson, 2017). An intellectual disability limits communicative and cognitive abilities to different degrees (Granlund and Göransson 2011), but all youngsters with ID require daily, life-long support from parents and professionals. Previous research shows that family members and professionals are the primary support group for these youths who also make use of new technology (Palmer et al 2012), even though we do not know much about how or on what basis this support is provided. Despite potential problems, the Internet can also be used as a 'free zone' by youths with ID, without the oversight of parents or professionals at special schools and/or group homes (Molin, Sorbring and Löfgren-Mårtenson, 2015; Sorbring, Molin and Löfgren-Mårtenson 2017). The reason is that many people with ID otherwise lack arenas for privacy, especially any connected with love and sexuality (Fish 2016; Löfgren-Mårtenson 2005; 2009). Furthermore, the Internet provides opportunities for the youths to explore and develop identities not connected to homogeneous labels of disability (Löfgren-Mårtenson 2005; Molin, Sorbring and Löfgren-Mårtenson, 2017). Instead, they can present themselves foremost as people with particular hobbies or as having other individual characteristics. However, a pilot study of parents and professionals has shown that the Internet is seen as a social arena with complex challenges for youths with ID (Löfgren-Mårtenson, Sorbring and Molin, 2015; Sorbring, Molin and Löfgren-Mårtenson, 2017). This group of young people is viewed as more vulnerable than other youths, and therefore at greater risk of being sexually abused or deceived in cyber space (ibid., Chadwick, Wesson and Fullwood, 2013). Nevertheless, the results of the previous study also show that parents view the risk of their adolescent being lonely as greater than the risk of being abused or misled (Löfgren-Mårtenson, Sorbring and Molin, 2015). The professionals who participated in the study view the Internet as a positive arena with options for love and social relationships, but are more concerned about issues connected to sexuality, such as sexual assault and pornography. Previous research shows that the majority of all young people have been in contact with

pornography, either involuntarily or voluntarily (Löfgren-Mårtenson and Månsson, 2010). However, the pilot study showed that pornography consumption did not seem to be common among youths with ID, even though it did exist (Löfgren-Mårtenson, Sorbring and Molin, 2015). Still, knowledge of professionals' experiences with Internet usage is limited and this article is part of a larger research project where parents', professionals' and the youths' experiences are in focus (ibid.; Molin, Sorbring and Löfgren-Mårtenson, 2015; Molin, Sorbring and Löfgren-Mårtenson, 2017).

Aim and research questions

This study aims to provide more in-depth knowledge about professionals' views regarding Internet use among youths with intellectual disability (ID), since their attitudes and conduct with regard to this subject are vital for this group of young people. Specifically, the aim is from the perspective of professionals to explore and describe experiences of Internet usage among youths with ID (aged 16–21 years), who are attending special schools. Of primary interest are experiences of love, sexuality, and relationships. The following research questions will serve as guidance as we proceed:

- How do the professionals describe the abilities of the youths with ID when using the Internet for social, romantic, and sexual reasons (e.g. friends, partners, pornography)?
- What kinds of experience do the professionals have of the youths' Internet usage, and how do they express their ways of dealing with this?
- In what ways do the professionals describe their own competence concerning Internet usage among youths with ID, and do they express any specific need for tools (e.g. policies, guidelines, further education)?

Method and theoretical framework

The qualitative method is used with the aim of gaining in-depth knowledge on this subject (Denzin and Lincoln, 2003), since the research area is underexplored (Svensson and Starrin, 1996). The method is specifically adapted to be used in a flexible way and to capture complicated aspects of the area (Kvale and Brinkman, 2009). An information and consent letter was sent by school leaders to four special schools, geared to pupils between 16-21 years, in a multicultural city in Southern Sweden with 300,000 inhabitants, who represent 177 different nationalities. The informants declared their willingness to participate by responding to an email, giving their confirmation. Altogether, 17 professionals, 4 males and 13 females,

between 29–58 years participated. They had work experience of between 2 and 20 years in the field. They worked as teachers, personal assistants, special ed teachers and head teachers of special secondary school programmes (henceforth referred to as 'special schools') for pupils between 16-21 years with ID.

One of the authors conducted the interviews in the various special schools where the professionals were employed. A semi-structured interview guide was used with a set of predesigned themes in accordance with the research questions. (See Appendix.) The interviews took between 45 minutes and 1 hour (and they were all recorded and transcribed verbatim). The data was then explored and analysed, using the software program MAXQDA 12. Categories were created based on the research questions, then transformed into analytical codes, and finally into themes (e.g. Widerberg, 2002).

Our analyses is grounded in the theoretical framework of Gagnon and Simon's (2005) classical sexual script theory. The term 'script' can be understood as an internalized manuscript for how, when, with whom and why to act sexually. Sexual patterns, norms and behaviour are then learned through social and cultural processes. The scripts can be placed on cultural, interpersonal, and intrapsychic levels (ibid.). The cultural script affects overall societal values regarding sexuality while interpersonal scripts organise relationships between people, and the intrapsychic scripts specify how the individual should act and react. Furthermore, the scripts differ according to aspects such as gender, disability, age, etc. Indeed, the scripts are never static, and the Internet is an example of a social arena that has altered the manuscript that informs sexual behaviour. Previous studies show that a Net-script, consisting of restrictive rules, is geared towards young people with intellectual disability (Löfgren-Mårtenson, 2008). That said, a turn toward a more flexible and nuanced Net-script is currently discernible since the group of young persons with intellectual disabilities is seen as more heterogeneous than earlier (Löfgren-Mårtenson, Sorbring and Molin, 2015). In this study, we use script-theory to analyse the professionals' descriptions of special school pupils' conduct on the Internet at an interpersonal level. However, we also connect it to the cultural script, referring to societal views of people with ID, as well as attitudes toward Internet usage.

The project follows the Swedish Codex of ethical guidelines concerning information, consent, usage of data, and confidentiality (The Swedish Research Council and Uppsala University,

2018). The ethical board of West Sweden approved the project (Dnr 048-15) and the study was adapted to comply with the Swedish code of ethics concerning requirements of information, consent, usage of data, and confidentiality.

Results

The result section begins with a description of the informants' experiences of the various abilities found among a heterogeneous group of young persons with ID. Thereafter follow the three themes that describe the patterns that appeared while analysing the informants' behaviour and attitudes: *A two-fold usage, Between being controlling and permissive*, and *A lack of strategies*.

Descriptions of the youths' abilities

The professionals at special schools describe having to deal with varying emotional and intellectual abilities as well as their technical knowledge in relation to the Internet use of youths with ID. This is challenging, and according to the informants, straightforward concrete ways of explaining and supporting are necessary. One male personal assistant explains:

It requires a clarity, especially towards those who haven't mastered the connection between emotions, acting, and thoughts. They [the pupils with ID] act based on their feelings all the time! You can't ignore that fact, but we don't always have the time to handle these things. [Interview 13, Male]

Several informants say that specific kinds of disability, such as autism and Asperger syndrome, lead to explicit social complications where Internet usage can be helpful. They describe many of these youths as shy, with feelings of insecurity and low self-esteem because of their difficulties with social interactions in real life. An option to communicate without face-to-face-contact can then be helpful. A female teacher talks about these positive aspects of the Internet:

Some may have autistic traits or be very shy. They might not be as much active in the community that so-called 'normal' youth are in. I think some of them have difficulties with direct contact and then it might be a little easier to hide behind the [computer]screen. [Interview 17, Female]

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However, not only pupils with autism have difficulties with their self-esteem and feelings of exclusion. The informants say that pupils with ID often have identity crises especially

connected to their difficulties in making contact with and developing relationships with friends and partners. Another female teacher describes this as a developmental psychological phase, and states that smart phones and social media help these pupils to feel like 'everybody else'. Not only are smart phones tools for communication, but also for navigation and a source for information. She explains:

Sometimes when our students are around 19 to 20 years old, they might have a small crisis, an identity crisis, so they are thinking: 'I'm not like everyone else, because I have no boyfriend or girlfriend' and 'What will happen to me in the future?' There are a lot of identity crises...like... 'I do not manage my life all by myself', and 'I cannot find my way in the city' ... So, I think the cell phone helps them to feel that they are a bit like everyone else. [Interview 9, Female]

Furthermore, the informants point out the importance of their immediate surroundings and social network, for example siblings, families and friends. They are part of the socialization process through interaction and representations, which is essential for youths with ID, just as it is for everyone else. In addition, brothers and sisters can act as role models as well as technical experts when it comes to Internet usage. A female personal assistant says:

I have a theory of my own, about those who have older siblings at home. They help [the pupils with ID] to 'speed up' the learning process, compared to what you can learn at lectures and in the newspapers and media. When it comes to this new stuff [e.g. Internet, social media], parents are seldom ahead [of their children] in this learning process. I think it matters how things are back home, and which groups of friends you belong to. [Interview 8, Female]

Theme 1: A two-fold usage

The professionals have an ambivalent attitude towards the Internet and view the pupils' usage as two-fold. On the one hand, many young people with ID are socially isolated and the Internet can function as their only contact network. The Internet is then an important and positive arena for romance and sexuality, as well as providing hope of making new friends and maintaining social relationships. On the other hand, the professionals view the Internet as a negative arena, full of hassles, bullying, sexual assault and sexual risks. They describe situations where other actors on the Internet take advantage of the young people's limited ability to understand Internet norms and conduct. This makes them especially vulnerable compared to other young people. For example, the professionals describe situations where

youths with ID have been persuaded to undress via web cameras or smart phones with the aim of becoming popular and acquiring new friends and partners without an intellectual disability. A female teacher tells of her experiences:

Many might not have such a large social network and if you have it online, it is great. However, they do not know who the others are ... They [the youths with ID] are often gullible and credulous, and can then be made to do things that they do not really want to. When you have a [intellectual] disability, then you are more vulnerable. [Interview 17, Female]

The easy, free, and anonymous access to pornography on the Internet and its influences on young people's views on gender and sexuality form another potential risk area, mentioned by several of the interviewees. When it comes to youths with ID attending special schools, this is seen as an even more complex aspect of Internet usage because of their difficulties in understanding these images of sexuality. However, the professionals do not regard viewing pornography as a common behaviour among young people with ID. One reason is that their private spheres are more limited compared to other youths, and visiting porn sites during school is forbidden. Another reason is that the young people with ID are viewed as more childish and more interested in hugs and kisses than in sexually advanced activities. Nevertheless, a male personal assistant stated that he is aware that some male pupils with ID do consume pornography on the Internet:

It can really be a mess when guys visit porn sites! They use their Wi-Fi back home, and their parents do not pay attention to it. Yes, there have been some hassles with some guys, when their computers freeze and we have to fix them. [Interview 11, Male]

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Theme 2: Between being controlling and permissive

How the professionals deal with the young people's Internet usage differs. Some act in a controlling way with limitations and restrictions on time and sites; others are more permissive and give the youngsters space, having faith in the pupils with ID. The variations do not seem to correlate to different professional positions, age or gender, but are very individual, according to the professionals themselves. It is up to each one of the professionals to decide how to react and respond on a personal level. One female personal assistant thinks that it is important to be supportive, and not to forbid behaviours. She explains:

One girl used to show me [friend] requests [from strangers], and tell me that she will block them immediately if she does not know them beforehand. Then I usually say – 'that is good, continue doing that!' I think that she manages to deal with these things. I only encourage her to do what she already has suggested herself. [Interview 16, Female]

Several of the informants state that they used to be more controlling a couple of years ago. Lately, there has been a change in attitude toward social media through a societal normalization process. Nowadays, most professionals use the Internet themselves in their everyday lives, which has made them more positive towards the young pupils' use as well. Nevertheless, the informants describe situations where they have to interrupt, control or interfere with the pupils' interactions on the Internet. These situations are not only connected to consequences of the disability itself, but to other factors that together with the ID add to their general vulnerability. Ethnicity is one such aspect that, as several informants explain, can increase the risk situation for the pupils. A female special ed teacher described one situation:

There were a guy and a girl that started a love affair on the Internet. And then it all went wrong! They sent pictures of themselves back and forth, and both these pupils came from another country. And then they pulled in Facebook friends from that country, and then we had to take a screenshot and check out what they had done and what was happening. There was a lot of gossip and accusations, and 'You're with all the girls' and so on, etc. We had to help them to sort things out [...]. It took the focus away from school activities [...]. We were forced to do something about it right away, it could not wait. [Interview 12, Female]

Sometimes the pupils with ID ask for help themselves. According to the informants' descriptions, the youths are often in great need of support from staff members because of their difficulties. It could concern a quarrel on a chat with a friend or partner that they cannot solve, or a snap chat with pictures that they do not understand the meaning of. Usually, the reasons for their need of support are misunderstandings due to their intellectual and communicative limitations, one female teacher says. Communication on the Internet is specifically complicated since body language is lacking, and the written word is usually the only source and tool for the interactions. The teacher continues:

Sometimes misunderstandings take place, and that happens quite often. Sometimes they express themselves [in weird ways] and don't really understand what they've said or what is written online. They are asking for help to find out about these problems. It is both ways [other times the

teachers interfere without initial questions from the pupils]. Occasionally there are conflicts in school because of what they have said or written. Then they show us what is going on [on-line] and say: 'Look here what she wrote!...' 'What should I do?'... 'Shall I go to the principal?' ... It's both ways... [Interview 17, Female]

Theme 3: A lack of strategies

The informants say that there is a lack of strategies, knowledge and policies concerning how to handle the complicated and problematic aspects of the pupils' use of the Internet at special schools. Situations that concern bullying and sexual harassment are examples that they mention, sometimes it is the pupils without intellectual disabilities who are the perpetrators. Many state that knowledge of how to deal with this should be part of a professional code of conduct, not be based on individual attitudes and experiences, but on shared guidelines and further education. One male teacher says:

It is frustrating... [...] I think that this is a shortcoming for us as an organisation when we don't deal with this professionally. Actually, we are here to inform and educate [the pupils with ID]. [Interview 13, Male]

Several informants are upset while talking about this subject area and ask for support from the head teachers, school administration and local council. Some state that the schools' basic 'Equal Treatment Plan' does not actually include pupils at special schools. In that case, should more situations be taken more seriously? Should there, for example, be police reports regarding harassment of pupils with ID? The need for strategies and action plans is a recurrent theme in the interviews. The interviewees state that 'The Equal Treatment Plan' is not enough; professionals at special schools need to know ahead of time what to do if there is a serious incident, and also who is responsible. One female teacher says:

We do have anti-bullying plans, but when things happen on the Net, I don't know if we have an action plan [Interview 12, Female]

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However, some state that they have had continuing education classes with external speakers, and that their head teacher supports their need for strategies. One female says that they have received training through a Pedagogical Centre (Interview 10, Female). Nevertheless, these statements are the exceptions.

Discussion – towards a participation-script?

The results show that the professionals at special schools have to deal with the youths' varying emotional and intellectual abilities as well as technical knowledge in relation to their Internet use. This leads to varying ways of conducting themselves towards the young people, and an analysis of their conduct highlights three themes that can be discerned from the informants' descriptions. The first theme that was discerned showed that some informants look at the youths' Internet-usage as two-fold; many young people with ID are socially isolated and the Internet can function as their only contact network. The Internet is then an important and positive arena for love and sexuality, as well as providing hope of making new friends and maintaining social relationships. However, the professionals also view Internetusage as a negative arena full of hassles, bullying, sexual assaults and sexual risks. This theme can be understood as a cultural script (cf. Gagnon and Simon 2005) on the Internet-use of youths with ID, containing a complexity of both positive and negative aspects on the subject area. Even though the Internet nowadays is an integrated part of communication as well as an information source for everyone, it is also seen as a place where specific vulnerable groups can become even more vulnerable. Cyberbullying and cyber-victimization are two of the areas that the informants mention and this is also a growing research area. However, Normand and Sallafranque-St-Louis (2015) remark that this is mostly connected to youths without ID. For example, current Swedish research shows a relation between poorer body esteem among victims of cyberbullying ages 10-15, compared to non-cyber victims (Frisén, Berne and Lunde, 2014). Jenaro et al (2018) show in a unique study of 269 participants with ID from Chile, Mexico and Spain that 15.2% have been cyberbullied and 9.7% are currently being cyberbullied. Being different was the main reason (97.7%) for being cyberbullied. Those who were cyberbullied reported being less adept at using mobile phone and Internet, as well as more unhealthy behaviours and depressions (ibid.). Nevertheless, Darragh et al (2017) point out the importance of using the Internet for creating new friendships, maintaining existing friendships, exploring and expressing sexuality. Their results also show that people with ID exercised cyber-safe practices without any explicit formal education and conducted themselves in a respectful manner. Few participants acted in a manner that appeared to put them at risk of exploitation (ibid.)

The second theme is understood as an interpersonal script (cf. Gagnon and Simon, 2015) where the informants' reactions as well as conduct towards the youth consist of a continuum from *controlling to permissive*. The results show that some are controlling and set limitations and restrictive rules on time and sites; others are more permissive and give the youngsters space, showing they have faith in the pupils with ID. These variations do not seem to correlate to different professional positions, age or gender, but are very individual, according to the professionals themselves. As mentioned earlier, previous research showed a restrictive and controlling Net-script geared towards the youths with ID (Löfgren-Mårtenson, 2008). The professionals' views on risk factors were predominant, such as sexual assault and bullying. However, the youths' view on risk was connected to the risk of disappointment in terms of not making friends, finding partners etc. on the Internet, just as in the 'real world' (ibid.) One way of understanding these contradictions is by using Breck's (2002) term risk communication. He argues that 'risk' is a social construction, just like 'participation', based on the context a person finds her- or himself in. Therefore, Breck advocates a democratic risk management, characterized by an early invitation to a dialogue with respect for the invitee's values as well as transparency in the formulation of the problem (ibid.). Löfgren-Mårtenson, Sorbring and Molin (2015) show a heterogeneous and nuanced script in their current research on professionals' views about Internet use among youths with ID. This could be understood as there being more of a dialogue nowadays, compared to the previous one-way-communication from the professionals to the youths with ID. In this present study, even though some informants describe controlling conduct, they also describe their trust in the youths' usage of the Internet. They talk with the youths, who in turn tell them about the ways they are acting. Thus, the Net-script of today might be described as a developing 'Participation-Script' where a continuous dialogue with the youths with ID exists parallel to the restrictive Net-script. The third theme is the obvious lack of strategies, and the need for continuing education and guidelines, that the informants ask for. They argue that knowledge of how to deal with the Internet use among youths with ID should be part of a professional code of conduct, not based on individual attitudes and experiences. The informants describe the youths as a heterogeneous group of pupils, with different levels of disability as well as a variety of individual factors. Hence, an intersectional perspective is needed to understand how factors such as disability sexuality, gender, ethnicity etc. interact as a basis for the development of strategies and knowledge development. Grönvik (2008) argues that this is particularly relevant for groups that may be perceived as marginalized and/or vulnerable. Intersectionality

is then about identifying how different power structures work together, depending on these various factors (Mattson 2010). This could be important in identifying those who have several vulnerability and/or risk factors and might require certain strategies, and those who have 'safety' factors which prevent the youths from being cyber-victimized. In line with this, the latter requires other strategies. To conclude, in order to develop the professionals' competencies in this area, the youths' diversity and their own voices need to be addressed.

Social pedagogy can contribute to new ways of understanding the 'h@ssles and hopes' experienced by the informants. The results show that in several aspects the informants have to find a balance between a participation script and a more restrictive script – or so to speak – school professionals are forced to handle and balance relations between 'the hassles and the hopes'. Hämäläinen (2003) claims the basic idea with social pedagogy is; '...to promote people's social functioning, inclusion, participation, social identity and social competence as members of society. Its particular terms of reference apply to the problems people have in integration and life management in different phases of the lifespan' (Böhnisch 1997 cited in Hämäläinen, 2003, p 76). According to Boddy (2011), a supportive relationship is about integrating personal and professional knowledge in terms of a 'professional heart'. Rather few studies have been concerned with supportive dimensions and people with ID from the perspective of social pedagogy. However, Carter et al (2012) represent an exception since they have studied how young people with ID can be involved in decision-making through the services they use. A social pedagogical approach was used to overcome obstacles for enhanced involvement. Similarly, Boddy, Carter and colleagues found that a social pedagogical support that balances between 'head, heart and hands' could provide the means to establishing egalitarian relations with young people with ID. As shown in the results above, everyday school situations are often about joint decision-making (c.f. Interview 16, female: 'I only encourage her to do what she already has suggested herself'). On the other hand, sometimes the professionals need to recognise the 'dialogic turn' in order to set up pedagogical situations where cognitive, emotional, and practical aspects of Internet use are in focus. Graham and Fitzgerald (2010) argue that we still haven't found a proper solution regarding the way we theorize, interpret and cater for children and young peoples' participation in everyday social and political life. They argue that it's not enough just to give children a voice and acknowledge their civic status. In this sense, participation is not

something that, in objective terms, can be 'assigned' to individuals and groups – it is rather that participation has to be 'created' and 'conquered' by means of a dialogic approach.

We have suggested that a participatory approach that seeks to facilitate the recognition of youths with ID entails much more than 'listening to them'. Instead, it points to the potential of the dialogic approach. Such an approach to participation is based on relationships that is oriented towards youths' self-understanding and individual agency, as well as to the self-understanding of the professionals involved (c.f. Graham and Fitzgerald, 2010, p 358).

Limitations

The study has several limitations. First, the number of informants is quite small and consists of staff members from a selected area in Sweden. However, the analyses of the seventeen interviews is profound and fits the aim of the article. Second, describing this vulnerable group of youths with ID from professionals' perspective could burden the group with a reputation for even more vulnerability, while their own voices are not considered. Nevertheless, ethical concerns have guided the process continuously and the young persons' voices are highlighted in another article within the same project (see Molin, Sorbring, Löfgren-Mårtenson 2017).

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Appendix Interview Guide

THEME: Experiences and knowledge

- Do you as a professional at a special school meet pupils with different cultural backgrounds who have intellectual disabilities (ID)? If so, give examples, please.
- Can you describe specific situations among the pupils with ID that are connected to honor-related experiences (HRE)?
- Do you and/or your colleagues have knowledge in HRE among pupils with ID, and, if so, from where did you obtain such knowledge (e.g., further education on the subject and/or supervision)?

THEME: Conduct and strategies

- Do you as a professional think that pupils with ID need professional support from you when it comes to HRE, and if so, what kind of support?
- Can you describe your conduct regarding how to meet pupils with ID concerning HRE?
 Do you as a professional have any strategies and/or guidelines?
- Is gender an important factor, or not, when it comes to how to meet pupils with ID concerning HRE? If so/not, how come?

THEME: Sex Education – a model on HRE

- Do you think that information about different sexual norms and cultures should be part of sex education? If so, in what ways?
- Should all pupils with ID attend sex education, regardless of their ethnic and cultural background? Why/why not?
- What do you need as a professional in a special school to work with sex education and HRE geared towards pupils with ID?

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Other comments