Submission to the United Nations Human Rights office of the high Commissioner Ms. Catalina Devandas Aguilar

Answers to the Questionnaire: The right to sexual and reproductive health rights of girls with disabilities

Sweden

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Equally Unique is a Swedish Human Rights Federation focusing on the rights of persons with disabilities according to the UN Convention on the Rights of Persons with Disabilities (CRPD), and the UN Convention on the Rights of the Child and the Convention on the Elimination of All forms of Discrimination against Women http://www.likaunika.org



Forum - Women and Disability in Sweden



The Swedish Disability Rights Federation (Funktionsrätt Sverige) is a federation for 41 national disability organizations with about 400 000 individual members. Our goal is a society for all based on human rights.

www.hso.se



RFSU – The Swedish Association for Sexuality Education (Riksförbundet för sexuell upplysning) is a non-profit organisation that works for an open, positive view of sex and relationship issues. We believe that everyone is entitled to be what they want to be, to choose to live as they want and enjoy what they want. We are convinced that sex and relationships are important, both for the individual and society. We work locally, nationally and internationally.

www.rfsu.se

I.Questionnaire

- 1. Please provide any information and statistics (including surveys, censuses, administrative data, literature, legal and policy documents, reports, and studies) related to the exercise of sexual and reproductive health and rights of girls with disabilities, with particular focus in the following areas:
 - Harmful stereotypes, norms, values, taboos, attitudes and behaviours related to the sexual and reproductive health and rights of girls with disabilities;

Historically people with intellectual disabilities have been heavily marginalized and regulated. From the 1920s to the 1940s eugenics, a form of racial cleansing, was practiced in Sweden (SOU 2000:20). The law against marriage between persons with disabilities is one of the consequences of such a movement (1920-1970s) aiming to to stop people with disabilities from having children. Another was the forced sterilization of people with disabilities, practiced until the 1960s (Grunewald, 2012). One of the results of the 1990's rights based movement was the 1994 Law on Support and Service (LSS 1993:387) that introduced and stipulated that people with intellectual disabilities have the right to a good life equivalent to that of people in the general society (Grunewald, 2012). Despite this law, people with disabilities have not become fully integrated into society as many have difficulty getting work and do not have access to the same material standard as others in the society. They often live in assisted living where residential staff continue to have a great influence over their lives, for example deciding when they should go to bed or whom they should have as guests (Grunewald, 2012).

People with intellectual disabilities are often considered to be asexual, childlike, oversexed or sexually inappropriate (Healy *et al.*, 2009; Rohleder & Swartz, 2009). This classification enables the argument that SRHR information for people with intellectual disabilities is unnecessary (Rohleder, 2010; Healy *et al.*, 2009) and makes invisible the sexuality of people with intellectual disabilities (Cambridge, 1998). This may lead to lack of development of information and services and that people with intellectual disabilities are given less space to express and develop their sexuality. Löfgren-Mårtenson describes people with intellectual disabilities as living in a silent world - not given opportunities to speak about their sexuality and sexual needs, nor taught self-confidence to voice their opinions in regards to SRHR (Löfgren-Mårtenson, 2004). Moreover heteronormative views of relationships can also result in cases where same sex relationships between individuals with intellectual disabilities are made invisible or trivialized, or might even be seen as a assault (LöfgrenMårtenson, 2004).

A further consequence of societal views is that people working with individuals or groups with intellectual disabilities have a tendency to protect their clients, which in practice is likely to result in infringements of their privacy and autonomy (Eastgate, 2011; Frawley, 2012; Kittay, 1999; Löfgren-Mårtenson, 2004; Rohleder & Swartz, 2009; Bahner, 2015). Swedish and British studies highlight the dilemma in finding a balance between the need for care and protection and an individual's right to sexuality (Garbutt, 2010; Lukkerz, 2014). Furthermore Swedish personal assistants lack national guidelines and/or regulations on how they are to work with clients' sexuality, resulting in situations where both employees and service users rights are infringed upon (Bahner,

2015). WHO also claims that the lack of access to SRHR information and services that people with intellectual disabilities face today is not related to the disabilities, but rather to societal exclusion (World Health Organization, 2009). This creates a structural discrimination where for example degrading views of people with disabilities or inaccessible crisis centers, prevent people from accessing the services they need.

Restrictions, imposed by others, whether in the form of limits to partners and opportunities to have relationships or restrictions to Sexual and Reproductive Health and Rights (SRHR) information, are not the only challenges to sexually active persons with intellectual disabilities. People who have been raised in protected environments tend to have internalized norms regarding their restricted capacities, in particular the capacity for sexual identity development (Kaufman *et al.*, 2007). The stigma of having an intellectual disability places great pressure on individuals to fit into society; so much so that some may put themselves at risk with the aim to appear normal (Rohleder, 2010). They may, for example participate in what feels like normal sexual behaviours, such as entering into relationships at any cost, or becoming pregnant (Rohleder, 2010). Restricting access to SRHR information is problematic as studies have demonstrated that people with intellectual and/or physical disabilities engage in sexual activity equal to that of their non-disabled peers (Eastgate, 2011; Löfgren-Mårtenson, 2004; World Health Organization, 2009). If one's access to sex, relationships and sexual health information is restricted it may result in risky sexual practices (Eastgate, 2011).

People with intellectual disabilities are known to be more vulnerable to sexual abuse, as without the appropriate sex education one may not be aware of what appropriate sexual contact is (Eastgate, 2011; Rohleder, 2010). Further, youth with intellectual disabilities are at greater risk of contracting HIV (Rohleder & Swartz, 2009; World Health Organization, 2009). There are also indications that people living in institutions, and who are dependent on others for care and daily living support, are more susceptible to abuse and violence (World Health Organization, 2009). There is to our knowledge no quantitative research on sexual health of people with intellectual disabilities in Sweden, although a report *on Living conditions of youth with disabilities* shows that youth with physical, mental and/or intellectual disabilities have a higher prevalence of risk behaviours than their peers without disabilities (Swedish Agency for Youth and Civil Society, 2012). A recent qualitative study indicates that access to sexual education and support for people with disabilities may be more restricted in Sweden than elsewhere (Kulick & Rydström, 2015; Swedish Agency for Youth and Civil Society, 2015).

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 - Sex education (in formal and non-formal settings) and access to sexual and reproductive health information;

According to WHO, the United Nations Convention on the Rights of Persons with Disabilities this group has both a need and a right to information and services concerning sexual and reproductive health and rights (SRHR). Nonetheless people with intellectual disabilities face restricted opportunities to exercise these rights (Frawley *et al.*, 2012; Kulick & Rydström 2015; Löfgren-Mårtenson, 2004; McCarthy, 2014; Rohleder & Swartz, 2009).

Sex education is a mandatory component in Swedish schools, including special needs schools/schools for pupils with learning disabilities, reports and research show that access to appropriate sex education is varied or non existent (Lukkerz 2014). Sexuality education is included in the curriculum for the compulsory school for pupils with learning disabilities and is thus mandatory (The Swedish National Agency for Education). As mentioned above, it seems to be a gap between the right to sexuality education and the extent and content of what is taught in schools. Despite this gap there is a interest and a willingness from teachers to teach sexuality education. For example, in May 2017 450 teachers and staff attended a two day conference on sexuality education specifically for special needs schools.

The National Agency for Special Needs Education and Schools, and the Swedish Agency for Accessible Media, MTM, under the administration of the Ministry of Culture have a mandate to ensure that all persons with reading impairments can access literature and daily newspapers through media appropriate for them. Theses

governmental agencies produce and adapt existing information, booklets, books and teaching materials for people with learning and/or intellectual disabilities, including sexuality and sexual and reproductive health material. Furthermore these governmental agencies have recently indicated their interest to cooperate more with The Swedish Association for Sexuality Education - RFSU. The National Agency for Special Needs Education:

https://www.spsm.se/om-oss/english/our-mission/accessible-teaching-materials/ Swedish Agency for Accessible Media: http://www.mtm.se/english/About-us/

A further marginalized population are people with hearing disabilities. The most acute shortcoming when it comes to sexuality education for Deaf and hearing impaired children and youth is that teachers often do not have adequate skills in sign language. They either lack the language to teach it, or they do not feel comfortable teaching sex education in sign language. There is an erroneous belief that sexuality education cannot be taught in sign language without being very visually explicit. This often leads to a very simplified sex education, or it is skipped altogether. For Deaf children and youth who also have cognitive disabilities the situation is even more severe. It is often thought that these children, especially girls, must be "protected", from others who would take advantage or abuse them.. Too often these good intentions lead to unfortunate decisions to shield them altogether from knowledge about sexuality, both their own and how to enjoy it.

There is a dearth of sign language material for teachers for sexuality education, and perhaps more severe is the lack of adequate education for teachers themselves. Many teachers simply do not feel they have the necessary tools to teach sexuality education in sign language.

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 - Access to child and youth friendly quality sexual and reproductive health services; and
 - Prevention, care and treatment of sexually transmitted infections;

In Sweden there are specific youth clinics targeting 13-25 year olds (the specific age range differs in each Regional district). The Youth Clinics (Ungdomsmottagningar) provide information about sex and sexuality; contraceptive advice and prescriptions; advice about abortions; and prevention, care and treatment of sexually transmitted infections to youth...Some of clinics are more specialized in meeting the needs of young

people with disabilities. The Swedish Society for Youth Centres (an umbrella association for youth clinics) have the intent to work for inclusion of all young people and to be accessible for all. The National board for Health and Welfare (Socialstyrelsen 2000) acknowledges the need for development of specialist competencies at Youth Clinics regarding disability and sexuality, especially in areas where the clinics are located near special needs schools. This work to make youth clinics accessible for persons with physical and intellectual disabilities has been initiated in some places, but not all.

57% of the Youth Clinics have easy reading information in Swedish. 89% of the Youth Clinics are accessible for persons in wheelchairs and 81% have wheelchair accessible toilets (Socialstyrelsen 2013).

Several NGOs in Sweden are using peer education as a means of working with people with disabilities. Peer education is an accepted approach for interventions related to sexual health in hard to reach groups. It has been found that peers are well equipped to exchange basic information in these circumstances (Frawley & Bigby, 2014). Research on peer education interventions has shown varied results in terms of long-term outcome measurements such as unwanted pregnancies and condom use (Osowole & Oladepo, 2000; Stephenson et al., 2004; Tolli, 2012). However, positive effects on knowledge and attitudes have been presented (Osowole & Oladepo, 2000; Tolli, 2012; Swartz et al., 2012). Frawley and colleagues (2012 & 2014) report on an intervention focusing specifically on the feasibility of peer educators with intellectual disabilities. Their intervention targeted violence in relationships and found that with adequate support peer educators could both provide information to their peers and develop their own capacity to prevent violence and support healthy relationships. A systematic review of sexual health interventions for people with intellectual disabilities indicated that most interventions lack evidence on the effectiveness of the program (Schaafsma, 2015).

According to the 2030 Agenda for Sustainable Development, goal 3.7, everyone should, by 2030, be ensured universal access to sexual and reproductive health-care services, including for family planning, information and education, and the integration of reproductive health into national strategies and programmes. The Authority Statistics Sweden (SCB) states, in a submission to the Swedish Government, it is a great challange to follow up the Agenda and measure the access to SRHR for persons with disabilities because disabilities isn't a principle of division (SCB 2017).

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Violence against girls with disabilities impacting their enjoyment of sexual and reproductive health rights; and

Violence against women reflects power structures between men and women, but other structures may also be relevant. According to the Swedish Agency for Participation, 18% of women with disabilities, between 16-29, have experienced violence or threats of violence, compared to 8% of women without disabilities. In the same age category, around 42% of women with disabilities are afraid of going out alone, compared to 7% of men with disabilities These figures indicate flaws in public investigation on harassment and possible hate crimes against persons with disabilities (Swedish Agency for Participation, 2015). Furthermore the National Strategy policy on violence against women define disability as a vulnerability factor for violence (Swedish Government, 2017).

To our knowledge, no data on sexual coercion exists specifically for persons with intellectual disabilities in Sweden although international data indicates that sexual abuse is equal to or above that of people without disabilities, both as perpetrators and victims (Brownridge, 2006; Eastgate, 2011; Horner-Johnson & Drum, 2006; Lunsky et al, 2007; WHO, 2009).

Children with intellectual disabilities have less legal security and certainty than others. Both Swedish and international science show that children with neuropsychiatric disabilities have three to four times the risk of being subjected to violence or abuse. These Children are often called "safe targets", as, from the perpetrator's perspective, there is a lower risk of being detected and convicted (Lainpelto, 2013).

A high proportion of children with neuropsychiatric disabilities appear to be subjected sexual offenses. 5-8% of children in Sweden have these neuropsychiatric diagnoses, but preliminary results indicate 13% of police sexual assault reports concern children with neuropsychiatric disabilities. According to the same research project police hearings are not adapted to individual's circumstances and needs. Despite the disproportionate statistics few perpetrators are convicted. Only 64% of the accused are convicted and 36% are acquitted. In comparison, for children without disabilities the corresponding figures are 86% and 14% respectively (Lainpelto, 2013).

- BROWNRIDGE, D. 2006. Partner Violence Against Women With Disabilities: Prevalence, Risk, and Explanations. *Violence Against Women*, 2006(12), 805-822.
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Swedish Government. 2017. A national strategy to prevent and combat men's violence against women, Draft (kapitel 5, sid 109-155) from Makt, mål och myndighet – feministisk politik för en jämställd framtid Skr. 2016/17:10

http://www.regeringen.se/4ad0bc/globalassets/regeringen/dokument/socialdepartementet/jamstalldhet/en-nationell-strategi-for-att-forebygga-och-bekampa-mans-vald-mot-kvinnor utdrag-ur-skr.-2016 17 10.pdf

• Harmful practices, such as forced sterilization and child, early and forced marriage.

Although forced sterilization is no longer practiced in Sweden, birth control use and hysterectomies are higher among women with intellectual disabilities, raising questions of how informed consent is obtained and if this constitutes a form of forced birth control (Greenwood & Wilkinson, 2013; Lindström, 2013).

A survey by TRIS (Girls rights in society) showed that there's a high prevalence of forced engagements and forced marriages amongst girls with intellectual disabilities, especially for young girls with parents born outside of Sweden. One third of the school staff affirmed having pupils who with were imposed restrictions on their choice concerning marriage, namely they were expected to choose a partner from the same ethnical or religious background as themselves. In 75 % of those cases, such expectations were posed upon girls.

Also, 47% of teachers replied having pupils subjected to forced marriage or forced engagement, all of them involving pupils with parents born outside of Sweden and 88 % concerns girls/female pupils. According to these teachers, 20% of those pupils didn't consider themselves as victims of forced marriage/engagement. In light of these numbers it is also important to highlight that 40% of school personnel state they have low knowledge of honor related oppression and violence (TRIS 2013).

The same report indicates many young persons with intellectual disabilities feel they are not allowed to have sex; 23% of girls and 14% of boys (with parents born in Sweden). Among those with parents born outside Sweden 70% of girls and 39% of boys believe they are not allowed to have sex (TRIS 2013).

GREENWOOD, N & WILKINSON, J. 2013. Sexual and Reproductive Health Care for Women with Intellectual Disabilities: A Primary Care Perspective. *International Journal of Family Medicine* 2013(642472) 8p.

LINDSTRÖM, S. 2013. Preventivmedel för personer med kognitiva funktionshinder: information, recommendation, tvång. Examensarbete i allmän rättslära, Juridiska Institutionen, Stockholms universitet.

TRIS. 2012. Triple exposed, report. http://www.tris.se/wp-content/uploads/2013/11/TrippeltUtsatt_TRIS-1.pdf

2. Please provide information in relation to any innovative initiatives that have been taken at the local, regional or national level to promote and ensure the exercise of sexual and reproductive health and rights of girls with disabilities, and identify lessons learned from these.

RFSU Malmö's project Sex for everyone is an intervention designed to create space and opportunity for people with intellectual disabilities to explore questions of relationships, sex and sexuality. The intervention is financed (2014/10 – 2017/10) by the Swedish Inheritance Fund and is run by The Swedish Association for Sexuality Education (RFSU) and Grunden, an organization run by and for people with intellectual disabilities. **Sex for everyone** is based on a modified peer education approach whereby

sex educators, with and without intellectual disabilities, conduct sexual health workshops in assisted housing units and adapted workplaces; aiming at increasing the participant's' agency in making sexual health decisions. The project leaders and sex educators jointly developed the intervention. This unique approach was used to ensure that the content and approaches used in the intervention reflect the sexual health realities of the target group and that people with intellectual disabilities maintain ownership of the intervention.

Key lessons learned from the project are that 1) Peer education is an effective and empowering mean to provide SRHR information to people with intellectual disabilities. 2) Film, pictures, and simplified text can be used to modify existing SRHR material so that it is accessible to people with intellectual disabilities. (For further information on the project and to download the materials www.rfsu.se/sexforalla. Note currently information and materials are only provided in Swedish)

RFSU Stockholm's project Signing sex (Teckna sex) is designed to to create a possibility for Deaf and hearing impaired children to get comprehensive sexual education in sign language and to find role models through deaf peer educators and films made in the project. Two success factors to highlight from the project: 1. The project leaders are themselves deaf which means that they belong to the target group and share the same experiences as the target group. This builds trust between the target group and the project since the target group does not have to educate the project leaders about their lives and experiences. 2. The project is carried out with a strong rights-based position, rather than needs-based. Our unyielding starting point is that sign language is a right, not a need. This is in line with what is stated in CRPD, but unfortunately sign language is increasingly seen as an aid to be used once non-signing communication has been tried (and failed), rather than a language in its own right. There is a heavy focus on auditory abilities, which means that it too often teachers, parents or other school staff decide how children should acquire information - through listening and/or speaking, or through sign language - rather than focusing on the student's own wishes and acknowledging that all children with hearing impairment have the right to quality sign language education, regardless of how many decibels their audiogram indicates they can hear. The project is funded by the Swedish Inheritance Fund.

RFSU Stockholm's project Sex in motion (Sex I rörelse) is designed to improve sexual health amongst young people (15-30 years old) with physical disabilities within the Stockholm region. The project wants to increase knowledge about sexuality and about how the non-normative body has the ability to sexual joy at the same level as everyone else. The project includes method development as well as education and discussion with the target group about sex, love and relations. The target group is often seen as non-sexual and has not had the same access to sexual education as others. This project will fulfil the need of knowledge and strengthen individuals' possibility to discover sex and relations just as everyone else in society. The project is funded by the Swedish Inheritance Fund.

The civil organization TRIS (Girls rights in Society) has published guidelines and a handbook on how to the work with persons with intellectual disabilities exposed to honor-related oppression and violence.