

Report on the sexual education of Adults with Learning/Intellectual Disabilities

Hungary



MGMA

PART A

1. Brief history of services for adults with learning/intellectual disabilities

Separated institutionalised care taking for people living with mental disabilities started to appear in Hungary a few decades later than in West-Europe. Until the Second World War children with mental disabilities were excluded from public education. Separated institute network did not exist, caretaking belonged to poor-case department, the disadvantaged people could receive help from the poorhouses.

After the Second World War the social administration changed, social politics became the government's responsibility. The previous system of poorhouses ceased to exist, as well as their name as poorhouse and love-home, the residential providing were not given on the basis of poor-rights. Expansion of room capacity was achieved by nationalisation of castles and private country houses. These institutions were usually far from populated areas, so their segregation was maintained as well as their previous caretaking methods and conditions.

By the end of the 1970ies, a concept for a unified care taking system was worked out. There was a significant capacity expansion between 1970 and 1990, the number of room increased from 27364 to 40857. The social law of 1993 about the social direction and provision created two distinct categories, care taking and rehabilitative provision.

In 2011, with the joining of two different projects and governmental help an institutional capacity expansion program was started, in the same time as forming knowledge for the physical and info-communicative barrier decontamination. In 2013 and 2014 six new institution will be formed. More info at: www.hozzaferes.hu

Some statistics according to data from 2006:

- About 40000 adults with mental disabilities are taken care of within families, this forms 0,5% of the country's population.
- Almost 13000 disabled people lived in homes for disabled people, they are nursing homes. (source: TeIR) ¹.
- 1745 people were accommodated in rehabilitative homes.
- 272 people were kept in temporary homes for disabled people.
- 1200 people were accommodated in residential homes, which provided care taking according to the age, health state and the degree of self sufficiency.

The maintenance of these institutions changed since 01.01.2013. Some of them are maintained by the county and/or the district, but there are also institutes that are run by the church or civil society organisations.

¹ TeIR (2006) Social Sector Informational System. Central Statistical Office, Budapest

2. Current Services:

Adults with disabilities get social support and pension-like financial support from the state. The social support is either family allowance or disability support based on mental disability, while the pension-like support is either rehabilitation or support based on physical disability. The right for the support is judged by assessment committee – the National Rehabilitation and Social Office. Apart from these, people with disabilities who live within their family can also attend daily institutional support, where they can participate in developing sessions during working hours. The Molnár Gábor Muhely Alapítvány (Gábor Molnár Workshop Foundation, aka MGMA) is also this kind of institution, and it is maintained by civil society.

Development sessions can be found in all of the residential homes, which help to aid the adults with disabilities to develop self-sufficiency and also they do some sort of work procedures there, it is some kind of social employment, where the state provides salary. Institutes where any form of sexual education can be found is very rare in Hungary. When some kind of institutional disorder takes place, which can be connected to sexual withdrawal, there is usually some kind of discussion about sexuality, but it soon fades away in practice.

Children's education

The Public Educational Act includes compulsory schooling: 6. §(3). Schooling is compulsory until the end of the school year, in which the student reaches age eighteen. In cases where the student has special educational needs, the compulsory schooling can be expanded to age twenty.

During the teaching of biology subject, some kind of sexual education presentation may be organised, but it is not a systematic or regular course. In the case of disabled children, sexual education is not taken seriously at all, which will cause greater problems as they reach adulthood.

For intact children, the biology lesson provides an introduction in 45 minutes. Unfortunately, the schools and institutions think that processing this delicate topic is solely the parents' responsibility. Neither the teachers, nor the parents are informed enough, and the relationship to their own hypocrite sexuality does not help the matter either.

3. Abuse and Safeguarding

In Hungary, just like elsewhere, there might be some cases when the rights of the disabled people are damaged, in the form of abuse, irresponsibility and sexual abuse. In residential homes, the legislation includes strict exclusionary measures, which are often inflexible and not humane. The general practice is that each institute creates its own institutional strategy in connection with sexuality. The Philadelphia Foundation from Holland worked out a "actional protocol" and its Hungarian version is capable to deal with all kinds of abuses.

The practice of guardianship in Hungary limits or excludes the opportunity for action and rights of the adults living with disabilities. In these cases the guardian, the parent or the appointed person, has the right for signature and can make the decision whether the looked after can have sexual life, can enter marriage and can have children. In 99% of the cases the decision is no.

There is no law, which would forbid disabled people to have sexual relationship, this is a conscious and moral question. Also, there is no officially published document, which describes abuses on people living with disabilities. Institutes are ashamed with such cases and they are kept in secret. There is a body, called TASZ, Society for Freedom Rights – www.tasz.hu, which investigates many doubtful cases. Another institute is the FSZK – www.fszk.hu – a non-profit LTD for Disabled Peoples Equal Opportunity. It was founded by the state and works against misuses and abuses.

The act of 1998, XXVI deals with the rights of disabled people and the provision of equal opportunity. Reporting and dealing with incidental sexual abuse is not developed. Every case is different, and if the abuse is reported to the police, then there will be a trial and judgemental decision. In Hungary this is a long, destructive and painful procedure.

4. Current arrangements for sex education for adults with learning/intellectual disabilities

There is no sexual education for adults with disabilities. There are some sexual psychologists who visit the institutes and give a 3-5 lecture course, if there is a tender or if the institute can pay for it. These lectures aim at the staff and the parents, but it rarely leads to a methodically built education for the people with the disability. There are no legal restrictions in connection with sexual education. The General Assembly of United Nations unanimously accepted the Agreement about the Rights of Disabled People and the protocols in connection with it. Hungary was the first to ratify the Agreement and the Protocol with the 2007. XCII law, although there is a lot of work ahead to fulfil its aims.

In Hungary, the problems connected to sexuality are not the consequences of intellectual disabilities. The reasons come from the everyday dependency, living conditions defined by the institute, and from those pedagogical consequences, that are drawn from their own imagination and from the importance they attribute to sexuality in case of the people living with disabilities.

The ethical values and moral norms define the frame, in which the sexual self-realisation can develop or get ruined. These social psychological and institutional factors can create a secondary associated handicap, which may influence the psycho-social conscious more than the intellectual disability.

The Hungarian national social attitude has developed a lot in the last 2-3 years, but it is still exclusionary. We can generally say that intact people do not support the marriage and childbearing. Although there are degrees, people rather accept love relationship, sexuality and starting a family on behalf of the physically disabled people, while people with hearing and seeing disabilities are not thought to be able to start a family and take responsibility. People with intellectual disabilities are not thought to enjoy human relationships on a higher scale, childbearing is forbidden for them in the perception of the intact people.

Taking contraceptive injection and pills is allowed in the institutes. Those women living with disabilities who live an active sexual life are given contraceptives. There some who understand the weight of this matter and there are some others with intellectual disabilities who do not understand this subject matter, but live active sexual life, they are better off with having injections.

5. Examples of current sex education for adults with learning/intellectual disabilities

In Hungary, it is not usual to have sexual education in separate lectures and workshops in institutes where disabled adults are looked after. There are seasonal lectures and there are trainings for staff and parents in connection with the topic. The Institute Handheld (www.kezenfogva.hu) started chargeable trainings in

connection with sexuality in which staff of other institutes could take part. Whenever a topic comes up in connection with the sexuality of the people living with disabilities the experts start to voice their opinions and their expectations, but then the topic will soon fade away.

The running of the institutes is financed by the state or the church, but they do not give professional guidelines. The institutes run by the church do not promote sexual education. The institutes can get sources for sexual education through applications and tenders, from which they can finance special programmes, like sexual education. Few institutes operate in the country, such as the MGMA, which embrace the policy that people living with disabilities are also emotional beings and allow them to have relationships and allows loving connections between the residents. Therefore, relationships and sexuality is present in the everyday life. Each life management, drama and other session includes such elements that are connected to gender, behaviour and hygiene. Music and dance sessions are also drenched with gender roles and sexuality. The residents like talking about sexual topics, moreover they tend to give it high importance among other aspects of being adult. The MGMA is able to give council to 60 residents and the same number of parents, and to a further 15 staff.

The institute re-launched the parents-club, it has sexuality as one of its core topic. We started family visits and we give high importance to the institute policy, which says that sexuality is the part of our everyday life, therefore it has to be talked about. Unfortunately Quality Assurance does not cover social sectors.

PART B - How people would like things to be in the future

Interviews with staff

We conducted staff interviews in Zirc, Pápa and Ajka, all of them are bigger towns in this county, where there are institutions for disabled people. First we talked to Fáró Katalin, in Zirc. In the institute the self sufficiency level of the residents is different. There are psychiatric patients, who have families and children, but the ones with mental and physical disabilities need more looking after, sometimes too much, on behalf of the parents, that they prevent them from being self sufficient. In their case dealing with sexuality is also in focus, as much as the parents allow. There were several incidents with both positive and negative results. Some parents can't accept that their children has grown up and said that their daughter is too little to have any kind of relationship with a boy, especially with another disabled person. The parents can prohibit and prevent any kind of relationship and by doing this keeping their children in childhood forever.

Once there was a sexual psychologist coming, who was not only going to talk about sexuality, but the emotional part too, but one of the parents had strong objections, she made a big trouble in front of the other parents. Although, this mother did not believe her daughter was disabled until the girl was 13, while her daughter had both physical and intellectual disabilities, so she does not live in the real world. The institute did not want to interfere at the session, they did not want to influence the parents. But then the aforementioned parent booted down everybody else, claiming that they are still children and they don't need any kind of enlightenment. Meanwhile, they tell each other in the institute what they saw on TV and on the internet, often porn too, so they can be quite heated and when they are here, together with the girls, they can feel their smell and can touch their skin, so they can't restrain their bodies' signs. The institute doesn't want to do things that the parents don't allow, but also they can't close eyes upon things going on during the day, this is true for all institutes.

They believe that everyone needs to have sexual enlightenment sessions, even if they are 35 years old on the level of a 5 year old mentally, because their bodies are older, and it works accordingly. They need to know why they have erection, what fluids their bodies produce. The parents are aware of this, because they bath them daily, so this enlightenment should be the parents' job, but they prefer to avoid it, because they think it is not necessary. Sometimes the parents ask the staff of the institute to talk about relationships with the young disabled people. They help in the frame that the parents allow. They let the boys and girls to have a

relationship in the institute, but they try to define the frame, because too much kissing and touching wind up the others too, and they all want to do the same, especially if they had been watching porn the night before.

According to Horváth Melinda, in Pápa, the sexuality is also part of the self sufficiency; they also have emotions and relationships, like anyone else. There are many friendships among the residents, and they always feel when something special is emerging between two of them, when the courting starts, there are some sessions, like dancing, where they have to touch and hug each other, so it can lush up the hormones and emotions. They organise other sessions for any kind of occasions, to have a 'party' where external guests from other similar institutes are also invited. There is a couple already with a boy from outside of the institute. According to the institute director, sexual enlightenment is the parent's job, but it is also a cultural question, although adults usually learn much from each other too and not only in sexual questions, for example the girls and women have to learn how to say no, how not to let men use them. They learn that love does not only happen if they have sexual intercourse, but there are steps to get there. They have to talk to them a lot and they also invite experts to talk to the parents as well as the young people with disabilities. The most important part in these sessions is not what a sexual intercourse is like, but how to be able to talk about it. Initially the parents did not want to be involved in the sexual questions, but they developed parallel with their children. There were a lot to do, first with the girls, they needed to know about menstruation, hygienic aspects, then doctors came to explain the biological aspects, functions and dangers. Then they built the sessions on these lectures, on how to do contraception, how to apply the condom, the dangers of chatting up somebody, the dangers of prostitutes. The parents had to learn too, that it is not enough to explain something once, they had to learn patience, they also had to learn to let their children exist. Every individual is a different case, they often acted out the scenarios, such as menstruation in bigger groups, which was quite a different approach.

They have a separate room, where couples can talk privately, but not only ones in love, but anybody who wants to talk privately on their own level of language. They are a bit freer in the camp, they might spread sun-cream on each other, there is more touching and kissing, the girls get prettier for the evening, hoping that the boy they like will be there. They haven't had sex yet though. The parents would not be happy about it, and it could have consequences, they are allowed to sit next to each other, hug each other and dance, but no sex. The girls are quite enlightened, by now, they know what they are or aren't allowed to do, so they won't do anything stupid.

According Erzsébet Tótfalusi, the deputy director and professional leader in Ajka, MGMA, they can make decisions on small things, like what clothes to wear, but they can't make greater decisions alone. Not solely because they can't, but also because they live in families and the family makes their decisions. It does not even occur in the intellectually disabled young person to make a decision alone. They don't think about getting injection against the flu, why would they want to get an injection, when it hurts? They make decision about who they are in love with, although it is overruled, because of the parents' influence they can re-think by the next day. Then the girl puts up with the parents' decision, she does not even consider the possibility to fight about it.

There are life-conducting sessions at the institute for improving self sufficiency. They have to learn the grades between love and hate, and the vocabulary in between, as well as the states that refer to those words, meaning for example that 'hate' does not mean the same as 'dislike'. They have the feelings inside, but they can't express them. All kind of gender role forms, then it turns out when they try to act it out, that emotions get in the way of planning. They want to say 'my love' in vain, when jealousy comes to the picture and calls her a whore in actual speech. The intention differs from the instinct when it comes to verbalisation. That is why they play a lot of situational games, so they might get used to count to three.

They also have computer sessions as part of the self-sufficiency education, so they will be open to the world. Using computers has become daily need and importance in everybody's life. It is important for them

to learn to communicate with the world and to create relationships. For most of them this is the only way to find acquaintances. Their life is quite closed, so using Facebook is a good window to the world. They often practice how to get to know people, what opportunities there are, how they can be used. They practice how they can have success, if they go out, they have to present themselves, how they can order a drink, what behaviour is common by other young people, but the parents don't let them go.

Interview with parents of three young people with intellectual disabilities

First, we talked to Richard's mother, whose second child is disabled, they wanted a girl instead of him and he has some girlish characters, like his cleanliness. He liked playing with dolls when he was little, and he also played with girls and he still likes children. They sew clothes for dolls, and they were painting and drawing. His mother doesn't think he could have a relationship. He is always interested in some girls, who are not interested in him. Although, once it happened in a camp that he got together with a girl, and he became much more open, he became a man while he was dancing with and hugging the girl. So, he is capable of love, he is respectful and fine-spirited. Although the mother has a fear, that he would not find anybody who loves him back and not just take advantage of him. He also had a platonic love, who was once kind to him and he followed her for years. The parents think he has right for sex, but they don't think he has tried, although he masturbates and the parents let him, they don't want him to be completely excluded. The parents would be happy if there was a right person for him, but if we look at our lives, there isn't really such thing as right person, there is no guaranty.

The second interview was with Betti's mother, she is a girl with physical disabilities, but not intellectually. She had a boyfriend from another town before, but she did not want him, nowadays she surrounds herself with friends on facebook and chats with them for hours. She has many male acquaintances and the parents are a bit worried, because they can't control her. The parents would be worried about her in a relationship. Because, she can't travel alone, so usually they take her everywhere by car, but in one case, she did not ask them, she had one of her friend to drive her. She said, that she was visiting a classmate, but she visited a man, she had met in the TESCO, who was 10 years older than her, he invited her and she went with him. I had the feeling, that he would take advantage of her, the disabled person. She didn't tell the parents, because she thought they would not be pleased. She claims she did not sleep with him. She was taken to the gynaecologist, but it was hard to talk to her into, to tell her it not only for woman who are pregnant. She can't accept her own body, she does not want to sunbathe or go to the beach, and maybe that is why she wants to stay away from sex, too. She doesn't like shopping for clothes, but electronic gadgets, she is not feminine. The mother is worried that she will not be able to find the right partner, but there are no guaranties in life, the development is constant. If the partners develop in life together it can be a success, but if they develop in a different rate, they might drift away from each other. The mother is willing to help her find a real relationship, instead of online chatting, she would even take her by car everywhere, because it is hard for her to travel, rather than exposing her to dangers on the internet.

In the third interview we talked to Laci's parents, both of them, it was interesting to see the differences between the father's and the mother's responses. They expected a girl, but had a boy, and when he was about two years old, it turned out, that he had intellectual disabilities. They didn't show much sexuality at home, the mother thinks it is the father's job to enlighten their child about sexuality, but he didn't go out much when he was a teenager, so his father didn't think it was necessary to talk about sexuality. He had a girlfriend before, and now he has another one who he does not see often, because they only meet when the families go to their holiday place. He would like to marry her, he was thinking about who to invite, and he was interested whether they could have intact children. The parents think the relationship can work, because she can cook and would be able to run the house, but they don't think about the sexual aspects. They don't know where to start, so they even attended sexual educational seminars. They don't think Laci has been with a woman before, but they know that he tried and was not successful, when the girl was

ready, he wasn't. He also needs to learn what it is like to be in a relationship, because when he was asked he said he needs a girl to cook, wash and have sex with him.

Interviews with young people with disabilities

Then we concluded interviews with young people with disabilities, first was Krisztián who has Down syndrome. He thinks it would be good if there was a session at the institute where they could talk about sexuality and relationships, finding a partner, because everybody wants to have a family. He said he would be brave enough to talk about these things with the others. He would like to know what the differences are between friendship and love and what happens if two boys fall in love with each other and when a baby is born the man becomes father straight away, or when. Does a man have to be ashamed if he has got a smaller penis? Do people have to be ashamed if they have a different body? How does a female body work? Why does it work so differently? – and questions like these. He would like if experts gave answers to his questions, his mates at the institute might have some experiences, but not enough.

We told him, that at the sessions he would have to use certain expressions to talk about sex, he laughed and said that he only knows rude and childish words.

He also had a relationship, with Kati, but they split up. He was not happy because Kati was not doing what he asked her to do. He told her not to talk to Adrián – another guy from the institute – but she did, so he stopped going out with her. But he did not ask anybody's opinion, he did not think that somebody could help him with this problem. It would be also important to know whether he can have a child, whether there will be money to bring children up, and where they would live, because his sister's family also live at his parents' house.

Then we talked to Juli, a girl from the institute, she also thinks it would be good to have some sessions where sexuality is talked about, because everybody wants to be with somebody eventually, although she thinks that the boys would make fun of the thing. So it would probably better if the boys and the girls had separate discussions, because she would probably not be brave enough to talk in front of the boys. There are some topics that are not interesting for the boys, or even they would be disgusting for them, like menstruation, but maybe it is better if they know about it.

She would like to know how the penis becomes hard, where does the sperm come from, whether it is good for the boy if the sperm does not come, how and where she can get contraceptives, what does the gynaecologist examine, how can a pregnancy be terminated, what does surrogacy and adopting mean, how she can get to know people, whether the partner finding web-pages are reliable, what emotional exploitation means, how can a relationship be humiliating, how does a man become infertile, and if he is impotent, will he ever have an erection. She was not sure whether she could accept her mate's opinions and explanations, because if they had known the answers for her questions they would have told her already. She knows the words that are used in connection with sexuality, but she is more interested in the emotional side of the things. When she was going out with Jócó, one of the boys from the institute, he wanted to have sex with her, saying that he only believes that she loves him, if she lets him to put his penis in her vagina, but her parents didn't let it happen, and he was driven away. Maybe he would still be there if she let him do it, but maybe her parents would still not allow them to meet, it's a big dilemma. She doesn't think she is ready to have children, also she would need a father, a man, a marriage, so it wouldn't be easy. What could happen if the father leave her, her parents would not let them go back home. For having children they would need to have a flat or a house, medical examination.

Then we talked to Arnold, another boy from the institute, he also thinks a sexual educational discussion forum would be very good to have, since relationships are the most important in life, they would probable feel uneasy and they would also be laughing a lot, but it would be nice to ask questions to find out things they don't know yet. He would be interested in the parts of vagina, how it is built up, what parts it has, what causes the erection, how can we know that the woman wants sex too. He would accept answers from

some of the others, but not from every one of them. He knows some vocabulary used about sexual organs, like pussy, oyster, jungle-rabbit, muff, Bermuda triangle, shell, cave and penis, cue, little soldier, crocodile, thermometer, sausage, snake, dick, carrot, tail for the penis and fucking, tossing, caroting, bench pressing for the intercourse. One of his mate claims that he knows everything, but he's very degrading with his girlfriend, so he's not a good example to follow.