

REPRODUCTIVE RIGHTS OF MENTALLY RETARDED PERSONS

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SUMMARY

Mental retardation denotes sub-average intellectual functioning, based on IQ, i.e. the inability of normal learning, accompanied by behavioral and developmental disorders. Persons with impairments (cognitive, motor, sensory or psychiatric) have often been, both through human history and today victims of discrimination and deprived of their basic human rights, both in the public and the private life spheres.

Since the end of the 20th century, throughout the developed world, many disabled persons can accomplish their dreams and rights. However, the issue of sexuality is still an obstacle in realizing oneself as a whole person, of course in accordance with personal psychophysical abilities. The greatest problem is present in persons with severe disablement, considered not apt enough for information on sexuality and for expressing themselves as persons with their own sexual needs. Thus it is desirable to observe each disabled person individually and flexibly enough in order to establish parameters for the functioning of an intimate affair on the level of understanding and assent. The legal system must protect the most vulnerable and ensure for them the right of choice and consent, as well as the possibility of fulfilling their sexual needs, so that they could love and be loved. Naturally, the system must be built on foundations that satisfy the needs of its users, but also of persons engaged in work with them. Sex education should contain information regarding biological, socio-cultural and spiritual dimensions of sexuality, including cognitive, affective and behavioral domains. Unfortunately, very few educational programs with such aims provide sex education, not only for the disabled young population but also for the healthy.

This review article is based on international investigations and Croatian legislative postulates. Its aim is to focus the attention of both professionals and non-professionals on this delicate problem.

Key words: mental retardation – ethics - reproductive rights - sex education - legislation

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INTRODUCTION

Psychological development presents the constant process of adaptation to biologically stipulated changes in growth, of achieving sexual and general identity, personality individualization, ability to chose life goals, activities and career, readiness and capability to accept ethic norms and behaviors typical for certain culture and society in its entirety (Dropulić 2002). Mental retardation denotes sub-average intellectual functioning, based on IQ, i.e. the inability of normal learning, along with behavior and developmental disorders. The prevalence of mental retardation in general population is 1-3% (Not 2008). Distinguished are: mild mental retardation, moderate mental retardation, severe mental retardation, profound mental retardation and mental retardation of non-specified degree. Among them approx. 87% of cases have mild mental retardation. These children are able to achieve academic status up to the 6th grade of elementary school and with little help can provide independent life for themselves. Severe mental retardation is found in 1-2% of cases (DSM IV; Dorsey et al. 1998). The cause of occurrence may be genetic (congenital metabolic failures, chromosomal aberrations), psychosocial (chronic lack of intellectual stimulation) and secondary as the sequel of disease or trauma (Kaplan & Sadock 1998, Durkin et al. 2000). Throughout the history of mankind, persons with

disabilities (cognitive, motor, sensory or psychiatric) have often been victims of intentional or irrational discrimination, and deprived from their basic civil rights, in both the public and private spheres of life.

THE SPHERES OF SEXUALITY IN MENTALLY RETARDED PERSONS THROUGH HISTORY

The diagnosis of mental retardation was mentioned for the first time in 1614. The cause was cited as “complete devotion to sexual pleasure”. Such an attitude, along with total neglect of sexual rights of the mentally retarded, has been maintained until the 40-ies of the 20th century.

One of the legal types of discrimination was compulsory sterilization of persons characterized as “sexual pervers” or “habitual criminals”. It was considered that they are inclined to criminal behavior and sexual promiscuity. The execution of sterilization, i.e. the eugenics movement, stems from the belief that mentally retarded persons are not able to give informed consent, and had the aim of preventing genetic transfer of retardation. From 1907 till 1957 about 60,000 people in the USA were sterilized without consent. Furthermore, disabled persons were usually confined to institutions characterized by the lack of any privacy.

Any hint of sexuality was misinterpreted and punished (Wade 2002, Elkins 1997).

In the mid 20th century eugenic sterilization was declared unconstitutional in the USA; thus the court recognized the inherited right of procreation for each individual. Groups of parents with disabled children began to emerge, recognizing sexuality as an equal right with the necessity of education according to the children's needs.

During the 60ies and the sexual revolution, positive shifts were made for this group of people as well, in the sense of greater sexual freedom and more independent decision making, but still not for persons with more severe mental retardation. The process of deinstitutionalization of disabled persons began, so many persons with more severe disablement were transferred from large to smaller institutions where they lived in smaller groups. Thereby the sexuality of these people started to be understood and respected.

Later, during the 70ies, the law on family planning was enacted in the USA. It stressed work on the education of handicapped individuals, i.e. all young people gained the right to sex education through social programs. Moreover, schools were expected to enable free and corresponding education for all children regardless of their psychophysical abilities.

By the end of the 80ies the process of deinstitutionalization of disabled persons was completed. However, a new problem emerged. It turned out that more severely disabled individuals were more prone to abuse. They become victims of sexual abuse twice as often as the healthy population and five times more frequently than other forms of abuse (physical, mental). Therefore laws on the protection of these people from discrimination and abuse were enacted. Hence, the endeavors in establishing these persons' independence, productivity and integration in the community were supported.

Form the end of the 20th century throughout the world many persons with more severe impairments have been able to fulfill their dreams and rights. They can no longer be confined to life-long institutions, be compelled to undergo unwanted sterilization, receive excessive amounts of medications, be isolated, be submitted to various aggressive methods of treatment and be without adequate health care. Special educational programs are being developed, common households are established, and trainings for qualifications is being attempted. Thus the attitude to their co-habitation with the healthy population and the recognition of their privacy rights has started to develop. There has been a shift from the traditional model of care for handicapped persons towards a model based on their rights and competencies. Of course, a lot of positive shifts are to be expected in the future (Health Scotland 2008, Wade 2002, Elkins 1997, Open Society Mental Health Initiative 2006). This is particularly valid for the Republic of Croatia. Although Croatia was among the first in the world to acknowledge the International Convention on the Rights of Persons with Disabilities

(May 3, 2008), it has not done enough in the improvement of life of mentally retarded persons with the aim of their inclusion into the local community (Human Rights Watch 2010).

REPRODUCTIVE HEALTH CARE OF MENTALLY RETARDED WOMEN

Routine gynecological care is an important part of health care for all women, especially during their reproductive age. It is valid for mentally retarded women as well. Adolescents and mature women with certain mental disabilities have special needs regarding gynecological and reproductive care. These requirements depend on several factors: the degree of mental and social disablement, life circumstances and developmental level. The existence of psychophysical and cognitive limitations, as well as previous traumatic experience during pelvic examination has brought about the fact that less than 40% of mentally retarded women have regular gynecological care (gynecological examination within three years) (Health Scotland 2008, Wade 2002, Elkins 1997, Open Society Mental Health Initiative 2006).

Pelvic exam is part of routine preventive medicine for women. However, for women with mental impairment, particularly those with reduced verbal and cognitive competencies, this examination is a traumatic experience. Various emotions can occur, from fear to anger, embarrassment and aggression. Due to these reasons, a gynecologist should foresee such reactions by detailed planning of the exam with the assistance of trained medical staff and the patient's caregivers. Education of the patient is essential, with the aim of explaining to her in a comprehensible way the purpose and course of the exam itself (verbal explanation, written and illustrated materials, three dimensional anatomic puppets). The patient should have an opportunity to ask questions concerning the exam and to hold in her hands the instruments used during the test. The feeling of control is very important to her. The involvement not only reduces the patient's qualms, but also enables education on the body anatomy and physiology. Thus foundations for bioethically correct informed consent can be established.

Guidelines for gynecological care for mentally retarded women:

- clinicians should be devoted in performing the best care for the patient;
- each patient should be treated as a unique person with her problems regardless of the level of her mental retardation;
- each problem should be considered as just one of the elements in the whole reproductive status;
- an intervention with the least possible negative consequences should be chosen;
- decisions should be made in a way sensitive enough in relation to social attitudes, and should be presented to ethics committees;

- certain procedures or treatments should be evaluated by ethics committees due to the problem of informed consent (Elkins 1991).

Women with mental impairments can have certain discomforts regarding the menstrual cycle. The premenstrual syndrome is very frequent and symptoms can be burdensome for them: weight gain, cramps, contraction seizures even seven days before bleeding, and behavioral changes (aggression, fury, tearfulness). Menstrual irregularities are also quite common, manifested as long-lasting, abundant or painful bleedings. Some patients molest themselves, so they need to be protected. Also, some women, especially those with severe and profound retardation, are not able to maintain adequate hygiene during menstruation. In such cases, therapeutic amenorrhea is recommended by pharmacologically aided menstrual cycle suppression. Those with mild types of retardation are capable of coping with their problems if given adequate education. Parents and staff engaged in care should be aware of these facts (Elkins 1991, Walsh et al. 2000, Kijak 2011).

It has been previously mentioned that coercive sterilization was in the past administered as a way of preventing unwanted pregnancy in women with mental retardation. Today it is not routinely executed. It is recommended in women with severe and profound retardation who are unable to perform personal hygiene of intimate body parts or due to gynecological diseases, severe anemia and other blood diseases, the existence of contraindications for oral contraceptives, and recommendations of the woman's personal doctor or legal guardian who considers that sterilization is the best solution for the patient. The data show that even 54% of parents speak in favor of sterilization. However, they should be acquainted with the risks of the procedure related to mental retardation (general anesthesia, postoperative complications) (Elkins 1991).

Criteria for sterilization in women with mental retardation:

- the woman is adult or in fertile age;
- she is sexually active or soon intends to be;
- mental disability is irreversible;
- she is physically capable to get pregnant or has regular menstrual cycle;
- contraception is not a reasonable possibility;
- she is able to give an informed consent;
- she is her own legal representative (Elkins 1991).

Various ethical aspects are connected with the sterilization of retarded women. These include informed consent, the right of the woman to privacy, and the consideration of the woman's interest. Informed consent is related to the woman's understanding of all options, risks and benefits of treatment, as well as the possibility of her expressing her own attitude to these aspects. In the majority of states it is necessary to have the informed consent of the person for sterilization. The consent of the family or guardian is insufficient. Above

all it is necessary to assess whether the woman is able to give informed consent. This process often requires the involvement of the court or authorized ethics committee in order to maximally protect the woman's rights. It must be mentioned that many experts, in both psychiatry and judicature are insufficiently educated for the adequate evaluation of informed consent, often using too broad or too narrow criteria for decision making for the existence or lack of mental capacities for giving a valid informed consent. It is therefore necessary to facilitate additional education of parties engaged in this process (Elkins 1991, ACOG Committee on Ethics 1988, Shah 2010, Goreta 2010).

Guidelines for the protection of interest in mentally retarded women when considering sterilization:

- irreversible mental disability or incapability;
- existence of fertility and personal sexual needs;
- to determine whether pregnancy presents serious and objective risk for the woman;
- to determine whether parenthood or maintenance of menstrual hygiene present a serious problem (ACOG Committee on Ethics 1988).

SEXUALITY IN MENTALLY RETARDED INDIVIDUALS

The majority of people do not ponder upon their health, usually they do this only when it is lost. Health is the cluster of circumstances: life expectations, functional status, mental welfare, social wellbeing, quality of life. Mental welfare is an important dimension of health. Basic components of mental health are cognitive and emotional functioning (Schwartz 2008). Regardless of the fact that mentally retarded individuals have a problem in recognizing, expressing and balancing their emotions, they need:

- to have privacy;
- to love and be loved;
- to develop friendships and emotional relationships;
- to learn about sex, sexual intercourse, safe sex and other issues related to sexuality (to protect themselves from sexual abuse);
- to implement their rights and responsibilities regarding privacy and sexual expression;
- to enter marriage and become parents;
- to develop personal sexual identity in accordance with age, social development, cultural values and social responsibility (Dorsey et al. 1998, Walsh et al. 2000, Štifanić & Dobi-Babić 2000).

It is known that the issue of sexuality is very important, particularly to young people. Healthy young persons very often mutually exchange information on this topic and get educated in this way, as well as through the media and family. We are witnesses that sex education is a political issue as well. Besides, in some countries sexuality is used as a tool for reducing the rights of women, particularly when certain psycho-

physical restrictions are present (Gardner 2002, Casas 2009). Moreover, investigations show that very few schools of medicine have programs to prepare physicians and other medical staff for delivering the courses of sex education (Dunn & Abula 2010).

Young disabled people cannot talk about sexuality with their peers because they attend special schools or classes for disabled persons. In these special school programs there is usually no talk about sexuality, although they are also individuals with sexual needs. Adolescents with mental retardation experience through puberty the same hormonal storms as their healthy peers. Their parents are daily confronted with numerous problems and thus simply do not have either time or strength to introduce conversation on the topic of sexuality. Exclusion of sex education as a part of the educational cycle for this group means discrimination and depreciation of their essential human rights. It must be mentioned that due to all these facts such persons are more prone to sexual abuse than the non-retarded, while unwanted pregnancies and sexually transmitted diseases are very frequent (Walsh et al 2000, Gust et al. 2003, Murphy & Elias 2006, Carpenter 2002).

The legal system must protect the most vulnerable ones and ensure them the right of choice and assent, as well as the possibility to realize their sexual needs and to love and be loved. In assessing competence, it is important to consider each individual separately and flexibly enough in order to establish parameters for the functioning of an intimate relationship on the level of understanding and consent (Carpenter 2002, Dukes & McGuire 2009).

Reed has proposed the following guidelines to be taken into account: 1) in evaluation for obtaining the informed consent the minimal levels of cognition, intelligence and voluntariness are necessary; b) very often the attitude of the population contradicts legal norms; c) the capability of a person to give consent is not static but must be re-evaluated after a certain period of time; d) standards need not be rigid but adapted to each particular case; e) all details related to the assessment of the person's ability to establish sexual relationship must be based on systematic and intelligible sex education (Reed 1997). A comprehensible sex education that will prepare the youth with severe disabilities for a successful and safe sex life is required (Department for education and skills 2003, Floyd et al. 2004). The aims of such a program that should be performed at schools are: information on body functioning, changes in puberty, on personal care and hygiene, health exams, social skills, sexual expression, contraception methods, responsibility through the respect of the mentality and self-determination of each individual (Murphy & Elias 2006, Carpenter 2002).

During the last 10-20 years many persons have developed their abilities on a larger scale, so their influence has increased in the field of work, education and functioning within society. Hingsburger has concluded that disabled people can develop sexual

relationships with others if they live in a healthy environment surrounded by people with adequate habits (Hingsburger 1991). Three components should be fulfilled in order to ensure the possibility for making a legal consent to intimate relationship:

- the knowledge of the important aspects of decision making, its risks and accompanying benefits;
- intelligence, reason or understanding which proves that the knowledge is comprehended and/or is applied in a manner consistent with a person's values or beliefs;
- voluntariness, meaning that the person is not subjected to coercion and understands that there is a choice and he/she has the ability to say "yes" or "no" to it (Wade 2002, Kaunitz et al. 1986).

Experts claim that persons with severe and some with moderate mental retardation should not enter marriage or have children, while persons with a mild type of mental retardation should have a limited right to enter marriage and have children in specific and very restricted cases. It has been proved that women with mild retardation often have a partner without intellectual deficit, while men with mild retardation very rarely enter marriage (Gallagher 2002). In the case of marriage it must be kept in mind that they can thus become victims of physical, mental and financial abuse by their partners, so the community must provide adequate protective measures (Disability Rights Commission 2007, Shaman 1978).

It must be mentioned that these persons, before entering marriage, must be provided with marital counseling regarding duties and responsibilities, sexual intercourse, contraception and possible sterilization before obtaining approval to get married. It has been observed that such marriages actually function well without children, while problems emerge with the coming of children (Shaman 1978). The question is how pregnancy affects a woman and whether there is any risk for the fetus, having in mind the mother's illness (the impact of pharmacotherapy). Thus the treatment of mentally retarded pregnant women presents a great challenge to medical staff engaged in their treatment and care. Health staff must be extremely tactful regarding their autonomy and decision making in regard to pregnancy, because they have a right to it. Thus this issue presents a great ethical problem (Coverdale et al. 2004, Zurak 2007).

RIGHTS OF THE MENTALLY RETARDED IN THE REPUBLIC OF CROATIA

On the basis of the Law on the Protection of Persons with Mental Disorders, each individual with such diagnoses in the Republic of Croatia has since 2007 the right to obtain care and improvement of health, including reproductive health. They have a right to education, involvement into family, work and social

environments, as well as the respect of personal choice, including the choice of an intimate partner, and sexual life, in accordance with their needs. Each individual, including the mentally retarded, should be comprehended through two components: dignity and individuality. Freedoms and rights of people with mental disturbances can be legally limited, if that is necessary in order to protect their health or safety. Restriction of their sexual and parental rights puts them into an unequal situation due to their mental status. Special measures that should be undertaken with the aim of protecting their rights or improving health should not be considered as a form of unequal action or privileges.

The cited law, as well as the Law on Health Measures for Accomplishing the Rights for Free Decision Making on Childbirth does not allow sterilization. Each individual, including the mentally retarded, has the right to decide, that is, to give consent and to express his/her choice concerning any medical procedure (including sterilization) if there are medical reasons for that (Zurak 2007). It should be stressed that the informed consent protects the autonomy and dignity of a patient, as well as the right of self-determination, which should be viewed through the prism of important social interests beyond personal limitations (NN18/78, NN88/09). When a person with mental disabilities is incapable to give consent, it is provided by his/her legal representative (parent or guardian). The first instance board decides upon the request for sterilization. The board consists of two physicians, of whom one must be a gynecologists, and a social worker or nurse, employed in the health care institution executing the procedure. The applicant can lodge a complaint against the decision of the board which refused the request within eight days to the second instance board whose decision is final (Turković 2009, Turković et al. 2001).

In 2007, the citizens of the Republic of Croatia with disabilities have obtained additional protection through the engagement and action of the public attorney for disabled persons, whose duty is among others to immediately lay charges to competent state solicitors if it is found out that a disabled person has suffered discrimination, violence, sexual abuse, molestation, exploitation, neglect or negligent conduct, to warn the corresponding body of state government and to propose measures for the protection of rights and interests of the disabled (NN 107/07). The non-government sector is also included in the protection of the mentally retarded. For that purpose the Croatian Union of Associations for Mentally Retarded Persons was established, which coordinates the work of individual local associations.

CONCLUSIONS

From all this can be concluded that there are legal frameworks for the protection of reproductive rights of mentally retarded people in the Republic of Croatia. However, a lot of time will pass before the rights of those people will no longer be considered as an obstacle

for accomplishing a partnership with the community. Persons with mental retardations, just as any other human being, have an innate sexuality, sexual needs and behaviors. Furthermore, as the World Health Organization recommends, mentally retarded individuals should be regarded as independent individuals who have a right and freedom to decide and act, because in such a way they are stimulated to live a normal life, the life of an individual unexposed to violations of personal rights and dignity. Only then can we consider their inclusion into society a completed process (Dropulić 2002, WHO 2005).

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