

Sexual Education and Disability: An Inclusive Pedagogical Study

Angela Magnanini

(University of Rome “Foro Italico”, Italy)

Abstract: Since the end of 1990s, sexual assistance to people with disabilities has been the systematical subject, on an International level, of many researches and investigations. Earle (1999), Tepper (2000), Shakespeare (2000), Waxman Fiduccia (2000) pointed out taboos and silence around sexuality, as nowadays the intersection between people with disabilities and sexuality has become an emerging issue of social justice (Shuttleworth, 2007) and sexuality is an inalienable right, therefore moving from a medical to a social and cultural perspective within studies in this sector.

The present study follows the same direction and, while trying to link together pedagogical knowledge and the results generated by researches within sociological, psychological and political sciences, aims at clarifying the figure of the sexual assistant, which a recent Italian bill wants to regulate, in order to promote “healthy sexuality and psycho-physical well-being of people with disabilities” (Parliamentary Acts, n. 1442, 9 April 2014), just like in other European countries. This assistant has strong educational values, thanks to the Italian inclusive pedagogical tradition.

Also this paper will therefore seek to develop an idea of sex education for people with disabilities as the final outcome of research that has attempted to reflect on three levels: (1) Socio-cultural; (2) Political; (3) Pedagogical. The final outcome of the research is to rethink the sexual education of persons with disabilities, presenting some lines of project guidelines in accordance with the pedagogical literature (Mannucci, 2002; Gelati, Malignano, 2003; Castelli, Mariani, 2005; Goussot, 2008; Lascioli, 2013; Castelli, Cereda, Crotti, Villa, 2013).

Key words: sexual education, disability, inclusion

1. Introduction

Vito Piazza was the director of a special school for people with disabilities in Milan (Italy) from 1981 to 1987 and his description of daily life in his school leads to the heart of the discussion and reveals in a nutshell the attitude that still prevails with regard to the relationship between people with disabilities and sexuality. Piazza speaks of denied sexuality and talks about Maurizio, who whenever liked a girl would begin to drool, toss and turn, taking his trousers off and screaming “wee wee, wee wee”. The teachers adopted a stance: they tried to ignore him and to direct his attention onto other things. Negative behaviour was not to be reinforced but contained (Piazza, 1992, pp. 66–68). The author concludes by stating that culture kills nature.

This example is important because, after over thirty years since those words were written, and even after many positive changes in the lives of people with disabilities in terms of education, employment opportunities and

Angela Magnanini, Ph.D. in Education, Assistant Professor of Special Education, University of Rome “Foro Italico”; research areas/interests: special education, inclusion, inclusive coaching, inclusive sport. E-mail: angela.magnanini@uniroma4.it.

independence, the topic of sexuality is still an open question, which is able to trigger long and passionate debates that go beyond the affirmation of the right of each person to express their own sexuality. Sexuality was studied and examined scientifically at first, both in Italy and abroad, in the late 1970s. At the same time in Italy begins the inclusion process of people with disabilities within education (with the first scholastic law about integration: Law 118/1971; Law 517/1977). This inclusive thrust characterized Italy from the rest of Europe (De Anna 2001, 2006, 2007).

On one hand, the studies about sexuality highlighted prejudices and taboos (Earle, 1999; Tepper, 2000, Shakespeare, 2000; disabled persons as asexual or perpetual children), on the other hand, they showed the need to find solutions or to develop cultural and operational strategies able to respond to the sexual needs of people with disabilities, which are often denied this need/right (Mannucci, 2002; Shuttleworth, 2007).

The intention of this paper is to outline one of the possible strategies, which is summarized in these key-words: accompanying, educating and liberating. These are three crucial phases to be assumed and completed in the process of recognizing a need and, above all, recognizing the person with a disability as just a person. Only in this case we could naturally consider sexuality as something common to everyone. These are three elements of an inclusive educational project. This is the only way to change the common attitude towards sexuality and to present a new image of the body, as something not to be subdued but cherished, rediscovering its satisfying instincts, pleasures and relationships (Mannucci, 1997).

This research is conducted through the theoretical approach of the Special Education, the discipline that studies the educational processes of inclusion (De Anna, 2014). From this point of view the issue of the relationship between sexuality and disability cannot be raised without considering education, an education that is open to sexuality and body (within its broadest meaning), and their essential dimensions: transmission and transformation (used in their intrinsic and extrinsic meanings).

The transmission of content, information and strategies have the purpose to help people with disabilities in the process of acquiring a whole series of concepts related to the subject of sexuality (from an affective, emotional and relational perspective, as well as from a biological one). The transformation of this content should enable greater self-expression and the research of personal solutions, rather than being passive recipients or victims of other people's choices. This process should stimulate individuals and communities to abandon a notion of sexuality that indefinitely perpetuates their ancestral fears (as it may happen in Italy, where culture is strongly influenced by Catholic Church), in order to produce a culture of normality. Sexuality is usually seen as an erotic act between a man and a woman who are healthy and married; everything else is immoral or unhealthy.

Therefore, the final outcome of this research is a concept of sexual education for people with disabilities that focuses on three levels: (1) Socio-cultural; (2) Political; (3) Pedagogical. The research focuses also on the debate that recently started in Italy (as in other European countries) regarding the role of sexual assistants for disabled people, which seems to be a topic crossing those three levels (reduction of social and cultural prejudices; political legitimization of a role: educator, companion or sex worker?). This role will be analyzed by examining the training programme devised by the Lovegiver Association (a committee for the promotion of sexual assistance, founded in 01/28/2013 and chaired by Maximiliano Ulivieri), the selection criteria for aspiring sexual assistants and the bill presented to the Italian Senate in April 2014, entitled Provisions on Assisted Sexuality for People with Disabilities. Focusing on this role allows us to envisage a broad concept of sex education, from which it cannot be excluded, according to the features that is assuming in Italy, with strongly educational characteristics and implications.

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2. Socio-Cultural Perspective: Beyond the Prejudice

The theme of sexuality/disability has always been experienced and perceived as unnatural, precisely because of a distorted view of the disabled person and his or her body (Berardi, 2013), which is often denied or unheeded, and, in the best occasion, is considered as something to be cared of (Magnanini, 2008). If sexuality is a prerogative of healthy bodies, in the case of a person with a disability, who has always been considered as sick, it is inconceivable. This approach, based on a medical interpretation of disability and on the influences of religious stereotypes, considers sexuality as a non-issue (a non-existent fact, as the focus should rather be on taking care of the deficit and helping the person to adapt to the social context) and, secondarily, as something to be condemned or sublimated. In addition to this, there are strong prejudices that have persisted for a long time with regard to masturbation and autoeroticism. According to Shakespeare (1996, 1998), there are numerous cultural and personal barriers that have prevented people with disabilities from fully expressing their sexuality, which can be summarized in six points: (1) Delay or lack of socialization of their emotional and sexual experiences; (2) Segregation in special areas for persons with disabilities, in out-of-the-way routes and locations; (3) Lack of sex education; (4) Physical barriers separating them from spaces and information; (5) Difficulty in expressing their sexuality due to excessive protection from associations, centers and families; (6) A lack of information about sexual assistance. In order to overcome these obstacles/barriers it is essential to work for a social and cultural renewal, creating new lenses and perspectives that overturn the prevailing convictions and allow the person with a disability to live through his or her sexed, lovable and loving body.

By means of a social approach, sexuality becomes something to “listened to” and “exercise”, thanks also to worldwide movements that have championed the rights of people with disabilities, such as the 1968 movement in Italy and the Union of the Physically Impaired against Segregation (developed in England in the 1970s). This opened the way to important documents such as the ICF (International Classification of Functioning, Disability and Health, 2001), which showed how disability is both a cultural and social product. In this perspective, disability is not an attribute of an individual but a complex interaction of conditions, many of which are created by the social environment. Strategies based on this model seek to create environmental, cultural, social and political conditions of accessibility, integration and active participation for all people with disabilities in all areas of life. Disability could actually affect anyone, at any point in their lives. For this reason, sexuality should be seen as a prerogative of each individual, man or woman, and as the expression of how they experience their bodies, emotions and pleasures, without referring to an abstract reality but rather blending in relational, affective and empathic situations. Sexuality can therefore be expressed in two possible ways, through relationships showing the desire to meet and exchange (components of eroticism, corporeality and pleasure), and as the free expression of ourselves, our own uniqueness and identity. These dimensions are built up through experience and education... if they are actually permitted!

These principles are well expressed by the Declaration of Sexual Right (World Association of Sexual Health), in Valencia (1997), revisioned in 1999 and in 2014: Sexuality is an integral part of the personality of every human being. Its full development depends upon the satisfaction of basic human needs such as the desire of contact,

intimacy, emotional expression, pleasure, tenderness and love. Sexuality is built up through the interaction between individuals and their social structures. Full development of sexuality is essential for individual, interpersonal, and social well being. Sexual rights are universal human rights based on the inherent freedom, dignity, and equality of all human beings. Since health is a fundamental human right, so must sexual health be a basic human right. Nobody can be excluded.

3. Political Perspective: Sexual Rights Are Universal Human Rights

Sexual rights are now considered as human rights, and their violation is a violation of the rights to equality, non-discrimination, dignity and health. With Decision no. 561 in 1987, the Italian Constitutional Court stated that “as sexuality is one of the essential forms of expression of the human person, the right to put it in place freely is without any doubt an absolute subjective right, which must be included among the subjective positions directly protected by the Constitution and viewed as one of the inviolable rights of the human person upheld by Article 2 of the Constitution”. Each person should therefore be given the opportunity, regardless of any disability, to make informed and responsible choices regarding their own sexual health and to avail of adequate opportunities and means, as reiterated by the UN Convention of the Rights of Persons with Disabilities. Policies must protect all victims of sexual violence (many of whom are people with disabilities) and promote initiatives to support a new concept of sexuality.

Bill no. 1442 (24 April 2014) on sexual assistance, presented to the Italian Senate by a group of senators, led by Senator Lo Giudice, stands right at the crossroads between these two aspects (social-cultural and political), anticipating the pedagogical aspect, along the lines of what was previously achieved in other European countries such as Holland, Germany and Denmark, just to mention a few examples. Holland was the first country, in 1980, to propose the idea of sexual service for people with disabilities, establishing an Association for Alternative Relations. It is interesting to know that in many countries these associations are organizing training courses for sexual assistants (e.g., in Switzerland and Germany).

3.1 Sexual Assistance

In Italy the movement was started, as mentioned above, by Maximiliano Ulivieri, who in 2013 formed a committee to promote this legislative initiative which highlights a particular aspect of the issue: the necessary support for the sexual dimension of people with disabilities through a service that provides emotional, affective, bodily and sexual assistance. This is not the only answer to the problem, but is a small piece of a broader plan aimed at overcoming numerous aspects of cultural conditioning. The bill presents sexual assistants as wellness operators that are to facilitate the healthy sexual and psychological-physical well-being of people with disabilities. These operators, after completing a psychological, sexological and medical training course, should be able to help people with physical-motor and/or psychic/cognitive disabilities to enjoy an erotic, sensual or sexual experience and to channel more effectively their internal energies, which are often discharged dysfunctionally in feelings of anger and aggressiveness. This bill is composed of a single provision and places this role under the aegis of the Ministry of Health. Each region will have to compile a list of professionals specifically trained to carry out this work, which can be a self-employed activity or can be exercised in a cooperative form, but may not form the basis of an employment contract or be put out to tender. To become a sexual assistant, a person must be of legal age, have completed compulsory education, be psychologically and physically qualified (certified by the Local Health Department), subscribe a code of ethics and have completed all the required procedures. Each Region can provide

training courses and monitor the progress of their sexual assistants (Casalini, 2013).

The objective proposed is to have professionally trained male and female operators that help people with disabilities to have a sexual experience but who are also able to perform the role of a sexual and affective education (Ulivieri, 2014).

This aspect is critical because it places the focus on the educational role of sexual assistants. As Quattrini emphasizes, sexual assistance is not merely limited to a mechanical act, but aims to assist and support people with disabilities to recognize, experience and exercise eroticism and sexuality (Quattrini, 2014). The meetings between the person with disability and the professional assistant can vary from 5 to 10 sessions and include educational and rehabilitative training in a continuum that ranges from informative, theoretical and practical aspects of affectivity to bodiliness, sexuality experienced through contact and through the use of massage techniques, the suggestion and experience of the sensory excitement of masturbation, and the promotion of education in orgasmic pleasure. Unlike in Northern Europe, and particularly to distinguish sexual assistants from prostitutes, coital sexual experiences, such as penetration, and oral-type experiences are not envisaged. Sexual assistance is seen as an experience of evolutionary growth, which is necessary for the person with a disability that requests it. It is organized as an educational process in which the assistant is entrusted with a role of accompaniment to the disabled person towards the discovery of their own bodies, affectivity and an intimacy they are so often denied. In this process, sexual assistants do not seek to create moments of segregation or isolation, but we could say that they rather want to coach and train the person for future meetings or relationships, as well as helping them to choose to embrace the precious and vital need of their sexuality. Employing the services of a sexual assistant does not mean creating a separate culture, but simply seeks to provide an opportunity in a context in which the institutions were often silent, particularly for those for whom access to sexuality is impeded by personal or contextual conditions.

Disabled people do not exercise their own sexuality and should not do so only with sexual assistants! Within the right conditions, people with disabilities can live a sexual and emotional life that is satisfying for both themselves and their partners.

Of course, cultural resistance continues to persist, which has meant that the bill is still under discussion and the courses have not yet begun, despite the fact that the first selection process has already been carried out.

The planned training course comprises 200 hours of training over a period of about 12 months, organized in monthly sessions, based on what is usually done in other countries. The theoretical aspects will focus on the study of disability from a medical, functional, psychological and relational perspective; assertive communication, active listening, emotions, empathy, and affective, bodily and sexual education. The experiential part will allow the applicants to question their own convictions. Two sexual assistants from Northern Europe will present their own experience and also allow techniques and theories to be tried out. Between 50 and 100 hours of internship will be carried out in associations and cooperatives participating in the project and monitoring activities will be conducted during the first year of the work.

Aspiring lovegivers (that's how sexual assistants are also called) were asked to submit their CVs and a motivational letter. Together with the clinical interview, they were also given the Sexual Disability Questionnaire (Quattrini, Dell'Oste) and assessed with the Balanced Emotional Empathy Scale (Mehrabian, 1996), the Emotional Fragility Scale (Caprara et al, 1991) and the Aggressive Behaviour Indicators (Caprara et al, 1991). They were also assessed with an emotive-corporeal perception tool (Quattrini), helpful for examining personal arousal dynamics and the exclusion of any erotic attraction towards disability (devotism).

In Northern European countries where sexual assistance and prostitution are both legalized, those who only

want to be trained in sexual techniques (prostitution) clearly require shorter and less structured courses than those interested in an educational process (Gemoyat, 2014).

The sexual assistant accompanies the disabled person in an educational process that allows intimate bodily knowledge, helping to promote a co-constructive process of pleasure and sexual well-being in three phases: acceptance (interaction and confidence), listening and contact. The individuals are taught how to do it for themselves, where possible. The aim of each process of accompaniment is precisely to let go and liberate.

The figure of the sexual assistant could be helpful in all those situations where the family or educator have to deal with this intimate and personal dimension, which needs to be restored to the person with disability through a process of educational accompaniment.

Up to now, operators and families have been informed and trained through conferences and seminars, and have often acted often.

4. Pedagogical Perspective: Sexual Education for All

This part tends to recapitulate all what we have said so far, knowing that the linchpin is found in education within sexuality, as a process of support and liberation. Liberation of bodily and sexual impulses, and liberation from constraints, barriers and prejudices. It is accompaniment in the etymological and pedagogical sense of *eo* ("go") *cum* ("with"), to go with, referring to the closeness between two people in a shared journey towards a common goal. To accompany in an asymmetrical relationship, which tends to reduce the distance, never substituting the other person, never acting in their place, but pointing out the tools for proceeding unaided. This is the sense of educational accompaniment that should characterize all the figures involved in the lives of people with disabilities. To strive for their independence, recovering a sense of their own body through a bodily education from the earliest age, in schools, that can give a sense of living and being a body with needs and impulses that should be listened to rather than denied. This is a prerequisite for educating towards sexuality, understood as learning to understand the message of our bodies and that of others, and to realize the potential of our being. Sexuality is relationship, contact, desire, pleasure and suffering, through a lived bodily experience, which does not necessarily require penetration.

At the initial stage, it will be the task of parents, teachers and educators to introduce people to these topics, including them, even in relation to other matters, in their own messages, teaching and educational activity, both in terms of information and of tools, exercises and contact, knowledge of one's self and one's body. The discovery of sexuality should also be encouraged in a personal way, without constraints and fears, which only suppress the capacity of being able to relate with others. This activity should not be restricted to disabled people, but carried out with everyone, because sexuality, as an encounter, requires the presence of everyone, regardless of their health conditions. At a later stage, it will be the task of individuals specifically trained as sexual educators or assistants to continue to accompany people with difficulties in this process of growth and emotional, affective and bodily experience. The essence is this: I know my body, I listen to it and I satisfy it... while respecting myself and others. I am ready for sex...

An inclusive educational project must have as a central point of reference the school, which is to build a culture of sexuality, even for disabilities. According to Lascioli, there are four areas on which to focus educational interventions: (1) Ludic: discover the personal body; (2) Emotional: discover the personal interior world; (3) relational: discover the body and the interior world of the other; (4) Ethics: discover the value of one's own and

others' corporeity (Lascioli, 2007, p. 353). In this sense, many of the school subjects could achieve targeted interventions, especially in the hours of physical education, starting in the most early age. Generally, the primary goal of sexual education is to promote adult "sexual health" and a positive image of the personal body. Schools should assist people in developing a constructive view of sexuality, providing them with information regarding the care they need to take of their sexual life, and helping them to acquire the skills they need in order to make decisions at present and in the future. The goals of sexual education fall into four areas:

(1) Information: Sexual education seeks to provide accurate information about human sexuality, including growth and development, human reproduction, anatomy, physiology, masturbation, family life, pregnancy, childbirth, parenthood, sexual response, sexual orientation, gender identity, contraception, abortion, sexual abuse, HIV/AIDS, and other sexually transmitted diseases.

(2) Attitudes, Values, and Insights: Sexual education seeks to provide an opportunity for people to question, explore, and assess their own and their community's attitudes towards society, gender, and sexuality (Banens, Marcellini, Le Roux, Fournier, Mendès-Leite, Thiers Vidal, 2007). This can help young people to understand their family's values, develop their own values, improve critical-thinking skills, increase self-esteem and self-efficacy, and develop insights concerning relationships with family members, individuals of all genders, sexual partners, and society at large. Sexual education can help young people to understand their obligations and responsibilities towards their families and society.

(3) Relationships and Interpersonal Skills: Sexual education tries to help young people to develop interpersonal skills, including communication, decision-making, assertiveness, and peer refusal skills, as well as the ability to create reciprocal and satisfying relationships. Sexual education programs should prepare students to understand sexuality effectively and creatively in adult roles. This includes helping young people to develop the ability to create caring, supportive, non-coercive, and mutually pleasurable intimate and sexual relationships.

(4) Responsibility: Sexual education tries to help young people to have responsible sexual relationships by addressing such issues as abstinence, how to resist pressures to become involved in unwanted or early sexual intercourse, and the use of contraception and other sexual health measures (Boehning, 2006).

The school can build an interdisciplinary sexual education path for all.

The four areas mentioned earlier can be treated in Science and Biology (Information), Philosophy, Literature, History (Attitudes, Values, and Insights; Ethics) and in Physical Education (Relationships and Interpersonal Skills), just to give an example of the many disciplinary combinations.

There could also be specialistic seminars made by experts, as the school must prepare the person in an integrated manner. In this direction, sexual education could finally help building a free person.

5. Final Consideration

A survey performed in ten classes of a secondary school in Ferrara in 2015, showed the need of students to address this issue in their own school. Among the 250 pupils, 10 of which with disabilities, responded in 95%, rising to 100% of persons with disabilities, the need to promote sexual education at school. In 90% of the cases, the students said that they never received information regarding sexual education, 6% of the students said they received this sort of education from their companions, and 4% from their families. Even just this reason, school should become a promoter of sexual education for all.

An inclusive educational project thus could develop a broad scheme involving schools (as the operational

center), families, associations and sexual assistants, working together, respecting the each other's roles, towards the full development and full participation of disabled people in everyday life: listening, welcoming, informing, accompanying and liberating! It is an educational activity intentionally aimed at making each person and their life journey unique.

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