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Advanced Needs for Disadvantaged People: Guaranteeing a Sexual and Affective Life Through Disability Services

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Abstract

This study presents a group of personal stories regarding disabled people who wish to have a sexual and affective life, most of them considering the explicit consent of the partner. They are handled by their original families and their socio-sanitarian services, which take care of them, but they experience difficulties handling these “delicate matters”. Workers and othe caregivers who take care of people with disability pursue pro-social and rightful mission. Sexuality is one of the basic needs of people, but there is cultural resistance on the territory, in services, operators and families who take care of fragile people, and does not accept this need or are not sufficiently prepared to consider it. Sexuality is a complex topic in this case; it triggers psycho-social aspects, but also medical and legal challenges which are often too complex for these people and for people who take care of them.

Keywords: Sexuality, Handicap, Community psychology, human rights.

Marco is a young man who, due to perinatal problems, has some cognitive and physical deficits; Lara is a girl with an extra chromosome, number 21, a genetic disorder better known as high-functioning “Down syndrome”. Despite Marco's horrible, endlessly argumentative character, she loves him and he loves her back.

The two young people met about twenty years ago: he lived with his mother and she lived with her brother but they met while attending the same daycare center. And there they fell in love.

After about ten years of tender love, the two youngsters are placed at the same time in a residential care center located in the Marche region. A few days after their arrival, Marco asks an operator for a private talk, saying that he loves Lara “to death” and is happy to finally live with her, but would also like they could share spaces and moments of intimacy. Lara is therefore summoned and, very tactfully, asked for her opinion. The girl agrees and reports that they have been thinking about the need to fully experience their intimacy for a long time.

With the couple's consent, the educator reports their request to the center manager and Lara's brother. The latter, just hearing about the topic, gets angry, stating “that he has never even taken Lara to the gynaecologist so as not to

traumatize her" and reiterating that his sister's sexuality is a topic he doesn't even want to hear about, abruptly closing the conversation.

The manager of the center, a place where workshops on affectivity have never been organised, concludes that intimacy between guests cannot be allowed in his facility.

Fabrizio is a guest of another residential center for persons with disabilities and suffers from a serious cognitive deficit with secondary psychotic symptoms for which he is under very heavy pharmacological treatment, which makes him very calm and is attracted to Anselmo, another guest of the center, also with a serious cognitive deficit. The center coordinator asks Social Services how to deal with and avoid these situations.

Lucio is a young man of about 25 years old suffering from a serious cognitive and behavioral disability and his father, Gianni, is an important businessman who works in high finance. Gianni has a very concrete approach regarding his son's fragility and seems to have a very open mind. The father demands to speak to the social worker who follows Lucio to talk about "important things". During the meeting, he asks how to manage the sexual needs of his son who, despite his cognitive and behavioral fragility, has never acted in reckless gestures or inappropriate behavior.

Ivana is a 19-year-old woman from a small village on the Italian coast; she is blonde and has big blue eyes on a model body. She is currently in her last year of high school and is being followed by social and health services for a mild cognitive deficit. She is an only child, and her family's parents work to exhaustion in the factory and have no time to dedicate themselves to anything else. It is the parents who discovered that Ivana, an adult and consenting, shot some hardcore videos that were shared. Parents, desperate, ask for help from Social Services to deal with the problem.

Objectives for the study

There is an African saying which tells that for a child there is a village which provides for his/her needs. People with a disability are like children even if they are adults. These people are under the responsibility of their families and specialized services. Unfortunately these groups of caregivers are focused only on the basic needs of these "special" people. The stories presented in this paper aim to verify next hypothesis

- H1: caring services and families – which in this study will be defined as "caregivers" are overwhelmed by population request
- H2: caregivers need to neglect some requests
- H3: caregivers tend to infantilize users, neglecting their more adult and complex needs
- H4: sexual affective needs are complex, are related with physical, but also psychological and legal aspects which are neglected since primary school times, even for normotypical people during their first years

Emotional responses

The main emotions you feel listening to these stories are anger, sadness and pain.

This kind of emotional reaction is often combined with the stories of persons with disabilities; their condition is often accompanied by reduced residual skills, especially in the area of autonomy and self-determination.

Fragility, the need for care and protection, and influenceability almost always lead to dependence on stakeholders, respecting the dignity and the willingness of these people (Lucas Mangas et al., 2023).

Disability can create labels that interfere with the individuality of a single person and lead to expectations of behavior or "non-behavior" attributable to the status of people with disabilities (Muzzatti, 2008).

People with disabilities have power problems where, by power, one might think mean freedom to be oneself. The need for care and protection implies delegating choices that affect their life to others. People with disabilities often give up shares of power to relatives, private professionals and services, placing themselves - totally or not depending on their residual capacity - in the hands of others (Castelfranchi and Falcone, 2010). Unfortunately, when it comes to power, it is often incompetent", such as when it is in the hands of a person who claims the right to be able to decide in place of another, taking advantage of a title or status that makes them think they understand what the real needs and potential of another person are (Carli and Paniccia, 2003).

Internationally relevant disability classification protocols and manuals, such as the WHO's International Classification of Functioning, Disability and Health (ICF) and the International Statistical Classification of Diseases and Related Health Problems 10th revision (ICD-10), the International Classification of Health Interventions (ICHI), and derived classifications, serve no purpose, as they are often not even consulted or inappropriately managed (WHO, 2001).

Often in adulthood, the person with a disability experiences that condition defined as "over-help", for which the person in need is considered unable to do certain things that are then managed by a significant adult (Leone, 2013). The effects of the helping relationship can be negative even if guided by positive intentions, making the people with disabilities truly incapable.

Complementary to this process is that described as the "Pygmalion effect" (self-fulfilling prophecy) by Rosenthal and Jacobson (Ianes, 2006), for which the devaluing attitude of people without disabilities toward persons with disabilities induces the former to stimulate little or discourage the latter towards objectives of improvement that are undertaken to a lesser extent by persons with disabilities themselves. The consequences often turn out to be that their behavior ends up endorsing the initial belief of people without disabilities about their being less capable, in a vicious cycle that is perpetuated (Muzzatti, 2008). In reality, universities could handle these people with "special needs" thanks to advanced technologies and techniques (Hernández Sancèz et al., 2024).

However, being in contact with people with disabilities also means interacting with families, when they are present, doing an extremely complex job that tries to fit together the various needs in compliance with the laws that defend citizens' rights, privacy, health law, rights of the workers who take care of them and the families with whom they deal. However, we cannot forget that it is no less important to also consider the rights, needs and potential of the patients themselves.

Structural vulnerabilities

On paper, Italy has advanced legislation regarding social and health services, particularly concerning the rights of people with disabilities. If, on the one hand, this can be a source of national pride and prestige, on the other hand, it has a negative value. First of all, it imposes particularly ambitious objectives for which occurs must take into account the sector funding that is not very generous and has been constantly declining in recent years. In the field of education, after the abolition in the 1970s (Law 118/71) of special schools and differential classes, in Italy, there has been a progressive development of the concept of "inclusion" of pupils with disabilities in the common classes of schools of all levels. Another law that marks the history of the rights of people with disabilities in Italy is the Basaglia Law (Law 180/78): the first and only framework law that imposes the closure of mental asylums and regulates compulsory healthcare treatment, establishing the hygiene service of the public mind. This made Italy the first country in the world to abolish psychiatric hospitals (Norcio, 1993).

However, cannot be forget how these two aspects, in particular, have been mythologized in a very ideological way, forgetting various flaws in the system and avoiding real discussion and critical thinking. The glaring limits of these organizational cultures (Carli, 2003) are addressed with rather inconclusive reforms and laws such as, for example, the continuous and disjointed reforms of the Italian school system starting from the second half of the 1970s; the slow closure of mental asylums and judicial psychiatric hospitals (OPG) without adequate replacement with alternative structures in the area; or the so-called "After Us" Law (Law 112/2016), which attempts to remedy the absence of the families of relatives with disabilities, leaving various areas and assistance projects uncovered for different types of disorders. All this, made worse by non-coordinated and predominantly political interventions, has built up an approximate and not very concrete plan, constantly and inexorably cutting coverage in terms of financing and leaving the institutions increasingly short of really competent managers, staff, and funds (Garofalo, 2016). The recent pandemic (which journalists, politicians and even representatives of educational and healthcare institutions currently mention using the past tense verb!) has done nothing but violently highlight the psycho-social suffering of the population and the inadequacy of services in the area. The fact that, in practice, health and social systems worldwide have collapsed like those in Italy does not console us sufficiently. It has often not been possible to manage the fragilities of the population and their most basic psycho-physical health needs (Antinyan et al. 2021; Banarjee et al. 2021), leaving communities victims of disorientation and misinformation at the health level but also civic and social (Fikukova et al. 2021); affecting different age groups with even extreme severity (Griffith, 2021; Jokic et al. 2020; Szimulewitz et al. 2021) and generating situations of disintegration of social cohesion and racism (Ransome et al. 2021; Taylor et al. 2021; Ye et al. 2021). Indeed, there have also been some timid attempts to address these problems with the mobilization of resources and through creative but inadequate solutions (Saleh et al. 2021; Soled et al. 2020; Surina et al. 2020).

Make the guidelines concrete

Necessities and needs: what is said in words must be made operational and guaranteed. A fascinating theory still used

today talks about the person's "fundamental motivations" or, better said, that constellation of internal and external factors that explain why the individual adopts certain behaviors at certain times. Referring to Maslow's "Theory of human motivations" (Maslow, 2022) in which the author represented needs as a hierarchical pyramid system where at the base there are elementary needs and at the top complex needs (Maslow, 2022). Very interesting, but also quite dated; we're talking about a contribution that is 70 years old (Maslow, 1943)! According to a more recent conception, the definition of "absence of disease" is implemented with the concept of achieving the highest possible level of health, understood as a "total state of physical, mental and social well-being". Citing more recent contributions, can be mentioned the famous concept of "empowerment" (Rappaport, 1995) understood as an objective and essential prerequisite for a healthier and fairer community without neglecting the need to customize assistance to the precise needs and potential of the user.

Community Psychology proposes some simple yet wonderfully effective techniques to increase Empowerment: understood as "an intentional, continuous and local community-centered process, which involves mutual respect, critical reflection, caring and group participation through which people, without an already pervasive share of valid resources, can more easily gain access to them and increase control over them".

Empowerment processes lead to the development of a "competent community", helping to create a widespread sense of social cohesion and sensitivity to the issues relevant to the community and proposing common action objectives (Cornell University Empowerment Group).

In the training sector (both in lifelong learning and in the school sector), integration projects concern people with disabilities, foreigners or fragile categories of people in general; in the organizations that take care of people with disabilities through the peer-counseling technique, the aim is to promote a better perception of the Self, the implementation of self-help and mutual support projects and a maturation of skills and abilities that allow supporting the achievement of rights through social inclusion.

The need to receive affection and physical contact includes needs that range from the desire to experience a romantic and modest sentimental relationship to needs more specifically related to the sexual sphere. When making these needs explicit, one often encounters resistance based on prejudices and social blame that, in the field of sexuality, find fertile ground. In 1993, the UN General Assembly approved a document in which all people with disabilities had «the right to experience their sexuality, to live within a relationship, to experience parenthood, to be supported in the education of their children by all the services that society provides for able-bodied people, including the right to have adequate sexual education". The UN hopes that, with this document, all Member States will promote the overcoming of cultural stereotypes that hinder the recognition of these rights for people with disabilities. What for people without disabilities is an individual choice, for subjects with disabilities is a choice that involves families and the social network who have the right/duty to protect, support and accompany the realization of their needs and desires. The testimonies presented above describe an anachronistic and grotesque scenario, recalling embarrassingly the America of the 1950s in the period of the Kinsey Report (<https://www.filosofemme.it/2020/03/31/il-rapporto-kinsey-sulla-sessualità/>) or the Italy of the Christian Democratic-style First Republic. Furthermore, these stories come from that part of Italy that claims to be moderately advanced and modern.

These stories speak of fear, hypocrisy and ignorance and strike us precisely because sexuality is an area of intervention on which the interest of cognitive-behavioral psychology was focused in its early years. Sexuality has always been the victim of great prejudices, misunderstandings, and dysfunctional beliefs (Fenelli & Lorenzini, 2012). Sex, especially when combined with a keyword that common thought conceives to be related to it, is destructive to a society that does not function. A bit like when we hear about sex in the third age, that is, something that we find inconceivable according to the "traditional" schemes adopted. In some cases, we even find it unspeakably disgusting and I bet that more than one reader will have instinctively twisted their mouth in a motion of infinitesimal disgust! The professional who talks about these stories can overcome the initial negative emotions by reading these stories, restructuring the dysfunctional beliefs underlying these stories and also grasping the fun that a free and mischievous person can have.

Marco and Sara are what we can define as "two sweethearts": they have known each other for years and are adults, uncensored and consenting. The services and families take care of them and support them regarding their needs and necessities at every level but, unfortunately, they leave out the panorama of affectivity and sexuality. Sara's brother has always put his sister's protection first, doing his best for her and encouraging her growth as a person but does not conceive of the possibility of creating spaces of self-determination in the sexual sphere. From her brother's story emerges fear mixed with reluctance at the mere thought of accompanying Lara to the gynecologist for "fear of traumatizing her". Not only that, the prevalence of this aspect of "overhelp" and excessive desire to muffle the life of a person considered fragile does not allow correct gynecological care, a practice considered essential to prevent any diseases. Even the coordinator of the residential center confesses a failure in the service, namely the impossibility of creating workshops on affectivity as intimate contacts between users are not permitted, as if we were talking about a religious college!

Concerning this question, we can hypothesize a theme that has not yet emerged: Marco and Lara have known each other for some time, and they have feelings; why couldn't they plan to have a baby one day? The possibility that a person with a disability wishes to have children has a detonating effect on a respectable society full of contradictions. In the religious sphere, a complicated paradox would be triggered: on the one hand, Catholicism condemns abortion (Jorge Mario Bergoglio states that «Killing is a sin against God, who is the Lord of life, against ourselves and others»); on the other hand, two disabled people, with a strong desire for parenthood, can be frightening and lead to a concept of sexuality as an activity merely aimed at the reproduction of the human race. Consequently, the sex of/for/with disabled people is to be rejected to «maintain the illusion of normality and sanity/ability of the group» (Monceri, 2012) which, on the contrary, would be lost if people with disabilities reproduced. A first mistake from an uninformed person: "But people with Down syndrome are sterile anyway!". Error: they are not, and they can generate; the risk is there! The two individuals could have families behind them who disagree and educators who feel they bear a more than complex responsibility. Lara certainly grew up in a limiting context that has not allowed her to delve deeper and functionally learn about this topic, so her "non-information" could generate the risk of an unwanted pregnancy.

Human sexuality cannot be reduced to instinct, pleasure, relationality and affectivity, but includes all of this in an unavoidable medium and long-term planning with meaningful horizons: sexuality needs such planning, tenderness, meaning, understanding, and sense of "givenness". In this framework, personalized educational projects, anthropologically

and pedagogically founded, take on value, which allow educators and other operators to address, discuss, harmonize and draw up a unitary line of accompaniment (Castelli, Cereda, Crotti, Villa, 2013).

Sexual education of people with disabilities remains one of the most delicate issues in the context of reflection on disability and the accompaniment of people with disabilities on the journey of life (Castelli, Cereda, Crotti, Villa, 2013).

The story we have talked about must make us reflect on what actions to take to lay the foundations for a project in the field of the sexuality of people with disabilities: "Emotion and sexuality education" projects, which are important for every type of person during development, whether they have "neurotypical or neurodiverse" functioning, must move in the direction of promoting shared reflection on these issues and accompany the individual in the exploration of their interpersonal experiences.

The case of Fabrizio, on the other hand, refers us to an even more complex question. The coordinator tries to prevent the "love between him and Anselmo". Once again, we are facing two consenting adults and someone would like to question their choices by leveraging their serious cognitive deficit. The operators of care centers and residential communities for people with disabilities often do not provide proactive support to the emotional and sexual needs of their clients due to the lack of an adequate training course and due to attitudes of moral condemnation towards homosexuality, whose expression is denied directly or indirectly (Meloni, Mele & Federici 2010). Homosexuality, moreover, can bring a certain turmoil in a group of men who may unconsciously feel violated and the object of desire of other users. Indeed, heterosexuality is binary, simple, linear and superficially even economical for organizations. As much as some media get away with some victimistic and paranoid messages, the world of sexuality overcomes a linear and binary separation and can mean a richer, more varied, complex and creative reality. Everything is easier to organize if, in the restaurant and the workplace, we find a bathroom for men and one for women. The real world is much more complex and this is not only because the media talks about "gender" as if it were a total novelty and a pompous product of political correctness. People with disabilities are often treated and imagined by society as devoid of sexuality and sexually "neutral". This is trivially demonstrated by the division of toilets for males, females and people with disabilities. Despite the persistence of areas of cultural backwardness, in more advanced countries, the freedom to live one's sexuality is guaranteed; this guarantee is also implemented through the inclusive use of language, just think of the possibility of including the "other" or "fluid" gender in the registry in addition to the masculine and feminine. The dichotomous simplification of male vs. female is sometimes also present in academic fields, in scientific articles and specialist texts. When we talk about sexuality and disability, we necessarily talk about the possibility of subjects self-recognizing, self-defining, and self-determining by expressing and enjoying their own intimate and sexual life. By appropriating this sphere and readjusting their own identity and practices, the subjects attempt to overcome in this way the limitations imposed on them not only by their own body but by the "ableist" regulatory system that sees all different bodies and subjectivities as incompatible with sexuality (Paglialonga, 2020). This complexity must be considered when we deal with users with disabilities, as it is necessary to also take into account the needs, fears and attitudes of the stakeholders. Sexuality, homosexuality and bisexuality were freely accepted during pre-Christian civilizations: just remember Alexander the Great, Julius Caesar, the Sacred Battalion of Thebes, Socrates, etc. In reality, well-known figures who went beyond binary sexuality were also present in societies after the advent of Christianity; only that they were condemned or often covered and hidden in a more or less powerful

way. The great writer Oscar Wilde and the mathematician Turing were strongly persecuted to death for their inclinations; stories of characters whose homosexuality was embarrassingly covered up, even if tolerated, are also known. Thus General Eugene of Savoy and Lawrence of Arabia were described as men who, sometimes, showed an excess of brotherhood with their comrades in arms, while others became uncomfortable characters like Pasolini and were accused of pederasty and perversion. Leonardo da Vinci and Michelangelo Buonarroti also had a free sexual life; this freedom found justification in the non-conformist and rebellious character of the artists who reached, in the case of Caravaggio and Virginia Woolf, unacceptable excesses due to their excessive impetuosity which distanced them from everyone. All the above characters were adults and autonomous, celebrated or criticized, but able to independently live their lives. Instead, in the context of disability, some decisions and activities can be delegated to others, and this can negatively affect individual freedom by not allowing them to meet. Here we are talking about people who, if they live in rigid contexts and are not in step with modern culture, have no way of escaping the bigoted ideas of the people to whom they are entrusted. Lucio and his father Gianni represent, however, an opposite case compared to the previous ones.

Lucio has some urges that, according to his father, will soon have to be managed. Gianni has no difficulty expressing the idea of a sexual performance by a prostitute. The approach of an uninhibited father takes inspiration from a patriarchal cultural model of a bygone era (what if it were a daughter rather than a son?) that does not consider possible emotional complications in the absence of an adequate education about sexual experience. In reality, Gianni talks about himself, his culture, his time, and his way of experiencing sexuality. He tells us, unintentionally, about a gap that separates him from his son's world, like the one that stands between society and disability. This is a shortcut that satisfies the duty of the caregiver rather than the needs of the person with disabilities. Ivana, with mild cognitive impairment, of age, and with good academic performance, has an active and consenting sexual life. So far, everything seems to be "normal". The situation is complicated by her propensity to shoot hardcore films and, above all, their diffusion online.

While abstaining from a moral judgment, we cannot overlook her cognitive condition, which may have exposed her, in the absence of adequate sexual education, to abuse and the risk of transmitting infectious diseases.

Conclusions

The varied world of disability, despite the indisputable progress of social integration that has allowed a better quality of life, has not yet benefited from a regulation aimed at promoting the right to sexuality. This is a legislative lack, in contrast with what was declared in 2001 by the World Health Organization, which introduced a new disability classification tool: the ICF (International Classification of Functioning, Disability and Health), which proposes a new, universal, multidisciplinary, person-oriented approach. According to the ICF, disability should no longer be considered as the condition of a minority group within a community, but as an experience that everyone can experience throughout their lives.

This condition refers to the "Bio-Psycho-Social" model, which pays attention to the well-being of the person in a holistic sense.

The bio-psycho-social model puts on the same level the biological aspects, the psychological dimension and the social

one to consider the person overall, equally contemplating strengths and weaknesses and thus avoiding a determinist reductionism.

The relational and sexual experiences that are intended to be made human rights concern the dignity of human existence. Their denial constitutes a clear violation of the right to equality. In 1993, the UN approved a document aimed at recognizing the right of all people with disabilities to experience their sexuality. It was recalled in the WHO Declaration of Sexual Rights in 2006, which emphasizes the right of all human beings to access and practice their sexuality. Disability and sexuality can no longer be considered through a prohibitionist perspective or, conversely, with an excessively liberal vision, without taking into consideration the many intermediate nuances that make the person with a disability a person, not a "type of person".

After all, sexuality, as an expression of a biological need, represents the only existential circumstance where "diversity" is not found. People with disabilities and people without disabilities seem to be equal in their need to express and experience sexuality, thus not becoming a minority compared to what the dominant culture believes to be normal. Despite this, people with disabilities continue to be considered a minority.

According to Moscovici, minorities can create a conflict in the uniform position of the majority and thus introduce an innovation. However, the conflict increases the tendency to reject the minority position. Only coherent minorities can produce acceptance effects, and it is in this sense that we must work. In the absence of this, even today, the sexual and emotional dimension of people with disabilities is considered a real taboo; it is perceived through deeply rooted stereotypes.

As in the case of ethnic origin, religion, and social background, without considering political opinion or the most banal sporting faith, in addition to the infinite forms of community experience, it is precisely through the observation of this unsatisfied need of this group of people that we can express a consequent evaluation of a society full of contradictions and malfunctions, and therefore imperfect. In the same way that anthropology serves to better understand our society by studying other societies, disability allows us to better understand the dominant culture of humanity, highlighting the differences within it.

In this regard, it is impossible to ignore the thoughts of the Polish sociologist Zygmunt Bauman regarding social stratification defined as "liquid" due to its clear fluid manifestation and lack of points of reference.

Yet, despite these considerations, the issue of disability connected to sexuality is still today conditioned by an anachronistic "right-thinking" culture.

In this context, using the figure of the navigator, we can say that a cautious approach to the topic is aimed at avoiding the storm, while a courageous action faces it and exploits its strength. People with disabilities should not be suppressed, should not be excluded, should not be treated with compassion or integrated but, more simply, included.

If integration is meant to physically bring people together, without allowing them to share the same tools, inclusion, on the other hand, offers the possibility for everyone to be citizens in all respects. The first case deals with sexuality between two

consenting adults with disabilities and allows us to remember how sexuality and sexuality education are fundamentally unknown topics, an experience left to instinctive practice, ignored in the school environment, making the question a taboo even for "normal" students. The case of Marco and Lara, as well as that of Fabrizio, must be able to represent an opportunity, a possibility to introduce the topic of sex education in disability assistance contexts and then be the subject of education also in conventional national institutions. Lucio and Gianni, like Lara, show us a situation where the theme of sexuality lends itself, according to the dominant culture, to an ideological interpretation of condemnation for reckless use of one's own body and others' bodies, or as an ideal to share, to a demonstration of consent. In reality, both considerations, correct from their point of view, do not consider the sexual experience of the person with disabilities objectively, that is, from a legal perspective.

This last consideration takes us back to the beginning of our journey into the world of disability; it takes us back to a territory without rule of law and without rights, where different people continue to be different.

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