
ETHICS IN CAREGIVING SERVICES FOR PEOPLE WITH SERIOUS INTELLECTUAL DISABILITIES

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Abstract: This article questions the reason behind ethics in caregiving services for people with serious intellectual disabilities, the reasons changes have taken place in medicine, in the kinds of illnesses, social changes and changes in how hospitality is envisioned, which lead us to reconsider the usual way of doing things, the traditional morals on which their treatment has been based. However, the traditional ways of dealing with those disabled individuals have also become obsolete and are ethically reproachable: based on charity and beneficence, goodwill and paternalism, if not on ignorance and vulnerability.

Likewise, we suggest that the concept of dignity be revived in order to serve as the underpinning of respect for people who are not autonomous, rather extremely dependent and will remain so for their entire life. Bioethics has unquestionably put too much stress on fostering and respecting autonomy, but it has not always outlined what kind of dignity should be recognised for a person who can hardly serve as their own moral agent. Thus, we suggest making a distinction between dignity in the lax sense, a dignity that everyone has, and dignity in the strict sense, a dignity that only a moral agent can have.

In this way, all people have dignity, both the most perverse murderers and the anencephalic child, but neither has dignity in the strict sense: the

former, because they have abused their autonomy and the latter because they are unable to exercise this autonomy. And we, the ones who interact with them, gamble with our strict dignity in how we treat them if we forget that they are always people, despite the immorality of the former and the disability of the latter.

We also stress the ethics that must be made explicit in services targeted at disabled people: civic ethics, or justice at the service of dignity; professional and organisational ethics, at the service of the disabled individuals' quality of life, with attention on the kind of relationship established with the patient and the families and their concepts of quality.

We finish by upholding the need, fundamentally in the institutions where these people live, to not depersonalise treatment. This depersonalisation takes place when the relationship is standardised *for the smoothing running of the centre*, when disabled people's degree of interaction or other affective-sexual dimensions are not taken into account.

Keywords: *Intellectual disability, quality of life, dignity in the lax sense, dignity in the strict sense, civic ethics, professional ethics, organisational ethics, charity, beneficence, justice.*

INTRODUCTION

In this article we aim to address the issue of why we need ethics in caregiving services for people with serious intellectual disabilities. To do so, we shall begin by explaining each of the words in the title.

By *ethics* we mean a critical-rational reflection on the customs or habits which are the morals (*mos-moris*). This reflection is conducted with a distance in order to see whether the moral responses that guide behaviour have become obsolete because they arose in a highly specific and determined context (a context with given values and knowledge), or whether they remain valid and why. The specifically moral question lies in what we should do, while the ethical question, by *antonomasia*, is why we should do it. In this way, what ethics is best poised to provide, and what we should expect of it, is the arguments and reflections that help us to later find the most appropriate habits, customs and values to provide

answers to the questions that reality poses us about what depends on us, about what is within our reach.

A *service* is always an interpersonal relationship in which someone does something for another person. A service is different to a mere product because its quality depends on the interpersonal relationship. And *caregiving* services are services in which one person cares for another. Kant reminds us that everything has its price, while people have their dignity. In German, *Achtung* means both attention and respect: attention means stopping, concentrating on the other, while respect, from the Latin *respicere*, means a watchful look (Esquirol, 2006, 65).

Autonomy means self-determination. According to Kant, the author who made the concept of autonomy fashionable (Kant, 2000) in the moral realm, dignity is grounded on autonomy, and precisely the people deserving of our care in this job are people who have dignity but no autonomy, and will never again have this autonomy, if in fact they ever had it. They are people with a *serious intellectual* disability. When a disability is intellectual, autonomy is hindered because the first condition for being autonomous is having the ability to grasp reality and information in order to be able to take decisions on it with the absence of obstacles or pressures (either internal or external) and in coherence with their own scale of values (Beauchamps & Childress, 1999).

Autonomy is always a degree on a continuum, a process during which we can self-determine to a greater or lesser extent, and in these individuals this degree is strictly curtailed. The people we are talking about here do not have this autonomy precisely because their *disability*, their lack of power, lies in not being able to think for themselves, nor consequently to live by themselves. Their disability is not partial, an inability to perform a given function, but serious. The cause of their disability is almost always a pathological process that is not only irreversible but also often degenerative.

Yet, following Kant, this does not mean that they lack dignity. It still makes sense to perform an ethical reflection on the caregiving services for people with serious intellectual disabilities precisely because they are still people. We must thus distinguish between two degrees of dignity: a *lax sense*, which everyone has as a person (end in itself, absolute value, source of all other value) who might have managed to develop autonomy if this pathological process had not occurred that impeded the intellectual development needed to be an autonomous being and be able to talk about dignity in the strict sense (Román & Gutiérrez, 2008, 427-434). Dignity

in the *strict sense* would be the kind of dignity that is the object of personal conquest, the veritable purpose of any moral undertaking that entails developing the degrees of personal autonomy, managing to think for oneself and living in coherence.

Thus, every person has dignity, from the most perverse of murderers to the anencephalic child, yet neither of them has dignity in the strict sense: the former because he abuses (Camps, 2006, 6-9) his autonomy and the latter because he is unable to use it. And we, those of us who interact with them, gamble with our strict dignity in how we treat them if we forget that they are always, despite their immorality or disability, people.

WHY THIS QUESTION TODAY?

CHANGES

If we wonder about ethics in the care of individuals with serious intellectual disabilities it is because either changes have taken place that lead us to question the traditional way of dealing with these people or new questions have arisen that we have not asked until now. Let us examine some of these changes.

Changes in medicine

In 30 years, medicine has changed more than in its entire previous history; these changes have always come under the euphoric umbrella of progress, that is, all changes are painted as being for the best, like a step forward. This has aroused in many people exaggerated expectations about the power of medicine, expectations that have often not been fulfilled. For example, medicine has made great strides in diagnoses but not as many in therapy: we might know what we have, but we do not necessarily know how to treat it.

With people with serious intellectual disabilities, we may know what they have, their diagnosis, but the most appropriate treatment will never wholly cure them, nor is it strictly medical-biological, rather it entails being cared for all their lives. For this reason, the care that they need and deserve should be not only health-related but social- and

health-related at the same time. Consequently, the doctors have to work with psychologists, with physical therapists, with social workers, with caregivers (often non-technical staff, but the ones who spend the most time with the patient), and they must do so in a team and with a multi-disciplinary approach.

Changes in kinds of illnesses

Due to techno-scientific progress, economic progress and progress in the welfare state, the life expectancy of many people with mental illnesses has been extended until they die of old age. People with disabilities can also live many years, a circumstance that did not hold true in the past due to social rejection, family negligence, a lack of social and health care and other factors. Longevity also generates other mental pathologies (Alzheimer) which extend life even though the person cannot improve, creating major medical and care-based dependencies for many years. Hence the need to adapt the laws (such as the law on dependency and the promotion of autonomy) and to create centres to house sufferers of both the new illnesses that trigger major disabilities and dependencies and the old illnesses that are no longer mortal.

Social changes

There have been major social changes: women joining the workforce has meant that care of these people now comes from outside the home and the family, as they delegate this responsibility to the centre. Furthermore, the very concept of *family* has become more complex.

Until relatively recently, different cultural or educational levels could be found at centres and residences, but not different cultures. Now multiculturalism, which is reaching these centres both through ill individuals and their families and through professionals and caregivers in general, requires us to explicitly outline the values behind the concepts with which we work, because they are no longer shared by *common sense*. This includes what we mean by quality, what meaning we assign to the *normal* concept of hygiene, meals, privacy and the like. These social changes make caregiving services in general more complex.

Changes in hospitality

When people suffer from a serious intellectual disability from which they cannot recover, they move into residences where they will live their entire life; the residence comes to be *their home*, which requires a certain kind of hospitality, a way of caring for them and being aware of their needs. This is quite different to a short or middle-term stay at a hospital or a centre, which the person knows is temporary, for a more or less specific period of time.

As the people we are discussing are chronic residents, we must reconsider what kind of hospitality we are offering them beyond treatments based on merely biological considerations, and what model of care. And it should consist of a great deal of personalised care because their stay is forever and personalised care makes the patients feel *at home*.

Right now, hospitality and the quality of care do not depend so much on the diagnosis as on the treatment, on the service as it is perceived by the patient and the family, who are the ones who end up taking the decisions on behalf of the disabled person. In these cases, the model of personal relationship between the social-healthcare structure and the patient and family is quite different to what is usual in other kinds of centres.

MORAL OBSOLESCENCE

Yet in addition to the changes to which we must adapt, there is also a need to spur change because the usual ways of doing things, our morals, also become obsolete. Thus, we must claim that people with intellectual disabilities must be cared for out of justice, not out of either Christian charity or Hippocratic beneficence.

Charity and beneficence

Traditionally, the religious orders, or the benevolence and altruistic beneficence of certain professionals, were what determined which service and which treatment, and they did so through their religious and altruistic morals. The goal is not to leave the care for these people in the hands of charity, mercy or compassion in a religious sense. This is a discourse that comes from religious perspectives, from personal maxims. Yet the ethics of people with disabilities has to *come first*, and the order of factors

alters the result, a civic ethics based on the *right* to healthcare. The idea is to provide a service that respects the civic minimums because care for these people must be guaranteed through justice and recognition of the respect that personal dignity deserves.

Good will and paternalism

Often this was dealt with not only from a religious perspective, but also out of paternalism and good will without the consent of the disabled person (within his limited capacities) or the family. It was thought that good will was enough, although as even popular wisdom claimed, the road to hell is paved with good intentions. That is, through paternalism society used to fall into the error of hyper-protecting and supplanting that started as good intentions but ended up in enlightened despotism: everything for the people, but without the people.

Justice demands the consent of the affected parties in conditions of information and symmetry. Obviously, people with serious intellectual disabilities are unable to give this consent, but we must underscore the fact that they are the subject of care, not merely the object of dedication and protection.

Ignorance and vulnerability

In other times, the families themselves, out of ignorance as to how to deal with people with disabilities, enhanced their vulnerability, and they did so from totally different vantage points:

Sometimes because they hid the people in the family who were not normal, thus creating an impersonal environment, secluding them and reducing them to a mere being, like a plant. By not fostering interpersonal interaction, they increased their solitude and their disability. They may have done so out of good will, to save everyone from suffering. Later there were efforts to combat this through normalisation.

However, in other periods society fell into the error of exaggerated normalisation, aiming to get these disabled people accepted and normalised into society. And they created the immersion of children at schools and then their job placement in certain socially conscious companies (some of which even aimed to be competitive). The problem then was that their

difference, their disability, was denied, because they were the same and deserved the same treatment. By wanting excessively to normalise, who they really were was ignored, people with disabilities compared to the abilities regarded as *normal* for living under self-determination and with a certain degree of self-sufficiency.

It is necessary to make people aware that these *creatures from another planet* (following the title of a book written by the mother of a girl with Rett Syndrome) (Pedrosa, 2008) can have convulsions at any time, and trying to introduce them into a normal school is good neither for them (it endangers their life if the school does not have many special conditions) nor for the other children (who cannot hold a *normal* class). What does normalisation mean when people are wholly dependent on an organisation? As psychiatrist Josep Ramos so aptly put it, abusing normalisation means denying the limitations of the disabled person, thus exposing them excessively to frustration and failure. Is dependency *normal*? However, denying their dependence to make them *normal* is a contradiction. They cannot have the same rights, and certainly not the same responsibilities. They deserve other, more specific rights because they are different. Precisely these individuals' capacity to take care of themselves is what requires us to reconsider the most appropriate treatment for their dignity, for their welfare, always accepting their difference, which is exactly their dependence on abled people. Dependency is not a shameful condition: the disabled deserve (are worthy of) special attention because they are special, and this is how their education, work, treatment and environment must be.

WHICH ETHICS?

ETHICS AS A CRITICAL-RATIONAL AND DIALOGIC EXERCISE

Since morals are becoming obsolete, since the sciences will continue to provide knowledge and make changes in the way we handle things and proceed, the habit that we must foster the most is the critical, ongoing reconsideration of our customs and habits based on the constant suspicion that the way we act is inevitably filled with prejudices, as Gadamer reminds us.

Habits, customs and arguments

We need more than morals and ethics, because this is what enables us to amend the different customs and habits that are the moral ones today and obsolete tomorrow. Ethics (morals considered) indirectly try, through the morals experienced, to guide decision-making in morally plural societies. It does so using the dialogic, deliberative methodology and based on internal, cross-disciplinary debate. And here the key, more than habits and customs, is rational argumentation, reasoning, acknowledging rightfulness, finding reasons: because by paraphrasing V. Frank and Nietzsche, whoever has a reason finds the how.

Truth and justice

This civic ethics is due to two categories. One is cognitive: the truth, understood as the validity of knowledge, a validity based on empirical proof, on the evidence we have at any given time. The second is justice, viewed as impartial treatment with the consent of the affected parties and in cases where we have to divide limited resources. We cannot take fair decisions without truthful knowledge, so we need the knowledge provided to us by the sciences. However, in order to have this information and be able to handle it, we need to guarantee the right to truthful knowledge, education and the freedom of research and expression, etc., in order to be able to give our free consent.

Goodness, according to whom?

However, this civic ethics, at the service of justice and truth, says nothing about world views, about quality of life, about goodness. Civic ethics talks about truth and justice, but not goodness: here impartiality and pluralism must be guaranteed. This means a very close relationship with everyone involved in the social services, namely six stakeholders: the patient, the family, the professionals (technical staff and caregivers), the organisation, the administration and society at large. Good communication among them, so that each knows what they need to do, is crucial. Consensus about what human dignity is and which rights befall each person based on their capacities (both personal and social) is also needed in order to later allow for a variety of notions of quality of life, of goodness.

ETHICS OF JUSTICE

We must foster a civic ethics, minimums based on human rights, which is the very content of justice. These rights are primary goods, top priority, the precondition making other more preferential goods possible. Rights are the minimum goods that any person should be guaranteed in order to enjoy a decent life on behalf of which they choose their quality of life. However, as mentioned above, a dependent person, a disabled person, requires other prior goods and needs *other rights*.

With the consent of the affected parties

In effect, this civic ethics is cross-cultural ethics with pretensions of universality, whose basic content is rights and whose method is deliberation and dialogue. In this fair way, the decision has the consent of the affected parties, who agree to the decision through information and symmetry (Habermas, 2000). Justice needs a procedure for its quest; it requires a methodology that is dialogic and deliberative. Thus, the dialogue and debate must be organised based on minimum rights that should be ensured for everyone.

In the case at hand, however, the people who are the most affected, about whom we are deciding much or almost everything, cannot take part in this decision-making process. For this reason, we must appeal to solidarity as the ineluctable complement to justice because the people affected by the decision are unable to have either information or symmetry.

This ethics must be on three levels: the macro level of social and health policies and laws on social services; the meso level of organisations, and the micro level of interaction between the professional and the patient, in the case at hand, of the disabled person and his or her family or guardian.

With these circumstances, the fundamental questions of an ethics of justice and solidarity in services caring for individuals with serious intellectual disabilities are:

- 1) What are the rights of individuals with serious intellectual disabilities? This is a question about our duties towards them in order to guarantee them a decent life, and it entails civic minimums.
- 2) What are the preferences of individuals with serious intellectual disabilities and their families? This is a question about the family's person

maxims and world views and requires an observation of the patient in order to ascertain what his particular welfare consists of.

3) What are the organisation and the professionals' possibilities, either enhanced or hindered by the administration and society, of *fulfilling* these demands? This is a question for the ethics of professional and organisational *responsibility*, and a question for social and health policies and the model of society we all want to construct.

At the service of dignity in vulnerability

A civic minimum entails ensuring decent living conditions for people with very little capacity to ask, demand and require. These people's rights must be quite different: their right to education cannot involve going to a normal school, but ensuring that they can maintain a certain degree of capacity within their disability should be a right.

The source from which almost all rights emanate is the right to self-determination, to freedom or autonomy. The people we are discussing here require constant, ongoing and extensive support from others: their main right is being cared for with dignity in a personalised way.

For quality of life

A fair life must make the quest for a good life possible. Since people with disabilities depend on others (professionals, organisations, families), they must find the time and ways of ascertaining how to improve the welfare of the disabled individuals, which requires, as we shall see below, an ethical attitude, willingness and availability.

Co-responsibility

As citizens, we are responsible for the place that disabled people have and occupy in this society; we are responsible for the image we give of these people, with the environment that we generate for them and with how we treat them. They are people with a very low capacity for self-determination for two reasons: because of their intellectual disability and because they have to live in a residence that must manage a large number

of people, professionals, families and residents. While this facilitates their dignity and quality of life, it also limits the capacities for individuality. We are co-responsible for managing the pluralism and diversity within certain civic minimums. And the responsibility is proportional to power and knowledge.

Professional and organisational ethics

Social service professionals cannot do this alone, nor can we, all the users, without them. Therefore, depositing all the ethics for caring for dependency and fostering autonomy into professionals is tantamount to demoralising them, to condemning them to being do-gooders who want to but cannot alone. For this reason, we must also speak about the responsibilities of the organisations or institutions where social service professionals work, of their professional associations and of social policy.

At the service of quality care

The purpose of professionals ethics is to legitimise quality. By quality we mean fulfilling expectations which are ultimately grouped under the categories of welfare and justice.

Quality requires expectations to be fulfilled. An expectation is appropriate when it is based on scientific evidence (it is true or false), it fits within the civic minimums when they are rights and responsibilities (it is fair or unfair), and last but not least, because the order of factors alters the product if it is good or bad. In effect, the quality of the professional service lies in the patient being satisfied, but as the user may be more or less informed or misinformed, the professional has a great deal of say over the quality of his services given the status of the laws and the research that only he is aware of as an expert in the matter.

Many factors converge in quality: the user's satisfaction, the status of professional knowledge, the professional's assessment of the services offered, the state of research, the possibilities that the organisation can offer in view of its limited resources, efficacy and more. The social service professional must keep abreast of the knowledge in his field (laws, therapies), must be a reliable source of information on this knowledge and must do justice when treating his patients and their families.

Politicians often arouse unrealistic expectations among citizens (the law on dependency) which *in the moment of truth* cannot be fulfilled because there are neither human nor technical resources. On top of this, social service workers also face personal pressures (they have to pay mortgages, schools, different insurance policies, etc.) and must obey like any other worker. However, they are also the ones who work directly, face to face, with the patient and the families.

It is the organisation's job to professionalise the caregivers; they are not professionals but mere technicians. Usually whoever spends the most time with the patient is not the most *technically* qualified worker. Making them feel professional, and responsible, for a service, for a person, representing the organisation, entails telling them that the job they are doing is much more than just a job. And this also requires in turn recognition of their value.

Social service professionals gamble with the credibility and trust in the profession because, in the end, all exchanges of services rely on trust, the main moral resource of any interpersonal relationship. The professional is co-responsible, both directly and indirectly: for improving the living conditions of the disabled person, directly, and for justice, indirectly. For this reason, he is responsible not only for applying the law (and not being negligent) and fostering the patient's welfare; rather he is also responsible for not creating a new or greater dependency on the organisation or the professional. It must always be ensured that the dependence and/or illness is not joined by new ailments, attacking non-malevolence and the beneficence: disorientation generated by arbitrariness in treatment augments dependence.

Thus for example, sometimes, for reasons of efficacy, because we have to go to work, or misunderstood friendliness, we fasten the buttons of the disabled person when he could do it, in his own time obviously, and after a few days of not doing it, because it has been done for him, we have created a new dependency.

At the service of organisational quality

The mission that legitimises the ethics of any organisation is also the quality of the service, but now quality encompasses several different professions, many individuals, users, neighbourhoods, regions in which the service is provided, and all of this in a specific, highly determined economic setting. Although professionals are needed, they cannot be left alone: the ethics of the organisation is needed in which they agree upon

the care model under which they must work, the coherent discourses that guide them and the arguments that must be given for why the families' requests can be granted or not.

The organisation is an important moral agent, and forging an organisational ethics requires many factors, including the following:

Working towards a *corporate ethos*, which is not merely the sum of personal styles. Instead, an *ethos* aims to outline what the organisation aims to achieve, how it means to achieve it, that is, the style by which it wants to be characterised and, if necessary, distinguished as an organisation within the sector, and the care model that everyone working in the organisation must promote. The goal is to agree to and explicitly outline how hospitality with disabled people is viewed.

An ethical *code* (with a committee in charge of enforcing it) can be an instrument for sharing the values and thereby outline the kind of actions and processes that the organisation expects of its staff. However, since we are dealing with ethics, the code should not be internal regulations; to achieve this, training, empowerment (responsibility is proportional to power) and care are needed, not just of the patient but of all the people working there. The values of residences are quite similar, but the important thing is how they are manifested, because this depends on the problems it has, the resources it has to manage them and everyone's willingness to deal with them. This is how agreement is reached on what the organisation considers good practice and why, and how it finds the mechanisms to foster this.

To generate *participatory democracy*: forums for discussion, participation and deliberation are needed where conflict is envisioned as a symptom of creativity and trust in change and improvement.

In coherence with the ethics of the patient's family

It would do well to recall that coherence does not allude only to the results or consequences. Coherence entails three ingredients: values and mission; actions and processes; consequences and impacts. One consequence might be that the family is very contented but the professionals believe that it is due to the preferential treatment they have received because of who or how they are. In this case, there is no coherence with impartiality and justice towards the other patients. Coherence is more complex when we cannot fall into homogeneous treatment and the family's values and world view must also be taken into account.

WHY AN ETHICS FOR ORGANISATIONS AND PROFESSIONALS?

THE AWARENESS OF COHERENCE AND BELONGING

Professional and organisational ethics are created only with the individuals that are part of the organisation, generating a certain feeling or pride of belonging to it. The professional represents and projects the organisation; he is the visible face of the organisation, and how and where the organisation is going largely depends on him.

Being aware of the degree of professional involvement of a person in an organisation is not such a complex undertaking. Simple questions like the following offer information on the degree to which the different professional ethics fit with the organisations: What does the organisation expect of you that you like? What does the organisation expect of you that you do not like? What does the organisation not expect of you that you would like it to? These questions must also be asked of the recipients of the professional service, in the case at hand the families of the disabled people we are caring for.

The major enemy of ethics is self-complacency: ethics are not developed out of narcissism, they are developed so that we all live together better. We develop them based on our condition, which is one of fallibility, and organisations must therefore manage their learning extremely well, because obviously we have no other alternative, sometimes through getting things right, sometimes through getting things wrong and sometimes through contradictions.

Technical training, training in values and in communication skills

Why do we need this professional and organisational ethics? Because professionals have usually received technical training but no training in values, at least they have never been told about the values that they use and that are involved with the technical skills are taught. This is because in a professional service, one that serves people, good intentions are not enough, not even with the question of personal self-realisation. One must also know whom we are offering the service, and offer it with personal treatment. And because *common sense*, which is the underpinning of the traditional way of proceeding, is not enough, and this underpinning changes according to the procedures and as the purposes we set for ourselves change.

Recalling that ethics primarily operates with arguments, we must improve the communication skills among professionals, between professionals and families, between professionals and the patient, and between professionals and the organisation. The fact that the night shift or weekend shift operates according to certain rules and the other shifts according to others generates a great deal of incoherence and arbitrariness, and therefore mistrust. Why do we need this professional and organisational ethics? In the end, it is a question of justice, solidarity, quality and trust.

THE RELATIONSHIP WITH THE FAMILY

The family is directly in charge of the patient and the ones to whom we must be accountable, as professionals and organisations, for the status of the person they have left in our care.

Autonomy: Respect for their personal ethics

Since they are the legal representatives of the patient, we must agree with them on many of the actions that we must perform as a centre. Yet we must also listen to certain unique family features that stem from their way of living and doing things. Here we must guarantee pluralism and strive to respect, to the extent possible, their uniqueness, yet always within the minimums we have established that guarantee the safety and dignity of the patient.

Communication: On treatments, diagnostics and courses of action

We have already said that the family is co-responsible, if they take the patient for several days, for shouldering the treatments, medication and cautionary measures that must be borne in mind for the personal safety of the disabled person. This often requires education by the professional because the family is not always aware of what to do.

Education on mutual expectations of the organisation and the family

If we want quality care, we must fulfil the family's expectations, and to fulfil them, we must be aware of them. However, these expectations

must be educated so that what is desired is responsible. The professional is responsible for the quality of his service regardless of the more or less well-founded expectations of the inexperienced, or uninformed, family, or another kind of extremely bossy, overly well informed family. Professionals' role as educators is unavoidable. Without the professional's education, reports, appraisals, clarifications of the new developments in a law, improvements and skilful use of devices, the family would not know what to do nor what they should expect.

Rights and responsibilities, understanding and comprehending

As the family, they also have rights and responsibilities, but since these people are unique, they must also take charge of the uniqueness not only of their family but of what they are responsible for. They have the right to come visit the disabled person, but they also have the responsibility to visit him because sometimes we think that if they have a right, others have responsibilities, yet the issue of rights and responsibilities is always reciprocal. This does not always hold true: the right to education also implies the right to get educated, not only the right to let others educate a person. Similarly, the right to take decisions on the seriously disabled family member also implies the right to share the co-responsibility for their dignity and quality of life, and since interpersonal relationships are crucial for quality of life, the family plays heavily into these interpersonal relationships.

THE RELATIONSHIP WITH THE PATIENT

The patient is the *raison d'être* of caregiving services, and the patient with a serious intellectual disability is a chronic patient. He will be at the residence his whole life; it is his home. Thus, we must first of all be clearly aware of the importance of the space that he inhabits and the time we spend on them. In order to provide quality care we must attach importance to the patient and his circumstances, to his surroundings. And the surroundings are extremely important. To begin with, we must make it clear that the surroundings are not just a space; either the surroundings recognise, shape, personalise and harbour or they can be impersonal and a kind of non-place. Surroundings which remain in a diagnostic or in

the label of *violent or aggressive person* are dangerous, as they give the patients up as lost causes.

With regard to time, we must be capable of finding it (time for observation, for getting to know the patients, for interacting with them): the excuse that we have no time to reflect on our model of care, on the quality and quantity of time we spend with them, is not an argument that ethics can accept. If we have to do something, we *can* do it. Therefore, we *have to* have a reflection on how patients spend their time, on whether there is some variation in the activities; how much time we assign to them depends on the pleasure they derive from these activities. For example, shower time: if we see that a patient really enjoys his showers, we can prolong them in order to give him his moment of wellbeing. Let us now examine several aspects of interpersonal relationships that must be forged with the patient.

Caring and touching

The personal dimension of the patient can never be forgotten; they have a certain interaction with their environment and are not pure vegetables. The patient must be treated as a person, and therefore given attention; they must be not subjected to attention but at the centre of this attention. The difference lies in shifting from being a mere consumer and observer and absolutely passive regarding the services already established, which are the same for everyone, to being able to feel that the services are for them (with their presence and communication, albeit minimum). Despite his disability, the patient often finds ways of being understood in a limited way, expressing pleasure, displeasure, satisfaction, esteem and unease.

Interaction and sociability

What impersonalises things the most is a lack of communication. For this reason, all punishments end up as a kind of exclusion or reclusion that hinders human treatment. We often fail to consider the person because he does not understand us, because he neither says nor does anything. This impersonal treatment denigrates all of us because we are not treating the patient with the respect he requires. As Serra very insightfully put it, our treatment of the disabled says who we are (Serra, 2008). Trying to

bolster their interaction and sociability via other means, because we are overly rational and verbal, implies having an extremely open attitude to finding out how and what they are telling us, in their own way.

Since these people have intellectual disabilities, they tend to replace their way of interacting with other means: the kind of touch, look, smile. In this sense, it is important to ask and probe precisely the person who does not ask. These patients who are so dependent are not exactly overbearing; even though they are very dependent they do not ask if we do not help them. Treating our equals as equals and unequals as unequals, Aristotle reminds us, is part of the principle of justice.

Careful looking and listening

We said at the beginning that respect for the dignity that every person deserves entails an attentive look. Here this attention deserves to be particularly developed. This means that we have to try to ascertain what the patient wants to tell us with that particular look, or that particular sound. And here we come upon an inevitable handicap, being willing to accept that we are starting with interpretations of what they are telling us, about whether there are improvements or not on what they feel about their needs for contact. And the danger here lies in replacing and projecting from one's own subjective vantage point. It is crucial that we know how to contrast our versions of events, our subjective interpretations, with intersubjective ones, the ones that dovetail with those of other professionals and the family, because what we think that we would like people to do to us is the result of our circumstances, sensibilities and pleasures, while their perspective might be different. Thus, the world viewed from their capacity must certainly be different. And it is our responsibility first and foremost (*primum non nocere*) to ensure their safety, their health (their disability often comes with other pathologies) and ultimately, for example, their privacy. Another person would prioritise privacy before safety as *normal*.

Thus, what happens when thinking about preserving patients' privacy is that we augment their vulnerability, endangering him by their falling in the shower or because they have convulsions that we cannot see because the shower has curtains to protect their privacy. However, the fact that the bathroom does not have shower curtains does not preclude the fact that the look must always be decorous. We must know how to prioritise

for the sake of their safety. The look and its intention furnish the ethical sense; their privacy is not being violated if they are being protected from a greater danger. The technical inspectors must be convinced of the unique features of these individuals.

Sexuality and intimacy

We tend to either neglect their sensual and intimate dimensions or simply project them as if they were not disabled. Sometimes the mental age of disabled individual means that he does not have a sense of modesty or a need for intimate contact, but that is not always so. Comprehensive care of the individual includes being attentive to his needs and desires and considering what would be best for him. Like the people they are, despite their disabilities, they have the dimension of sexuality and a certain sense of intimacy. Respect for their integrity entails accepting them as a whole: we should not foster a sexual dimension that they do not have, nor should we ignore it if it develops (Gafo, 1992).

Personalisation and homogenisation

We must avoid a hyper-regularity of habits (always the same). They are people and deserve differentiated treatment within the realm of the possible. Routine provides order and balance, but the Greeks said, “nothing in excess”: regularity without exceptions, a mechanical regularity turns everyone into machines, regardless of who is being served and who is being cared for.

Impersonalisation tends to be the result of homogenisation. It is true that in a place where many people live together there have to be rules, but just as we are capable of understanding a medical prescription for one ill person’s food allergies and another patient’s diabetes, in services targeted at such severely disabled people we have to personalise the care, which includes personalising their habits, even if only minimally. Residences tend to be large centres with many professionals and patients. Obviously we all have to be accommodated, but the services are there to serve whom? The comfort and efficiency of the professionals and organisations, or the welfare and quality of care of the patients? Welfare and quality entail promoting differentiated and personalised treatment to the extent possible.

Everyone the same, scrubbed and polished, everyone at the same time, in the same room, leads one to think that the services are organised based on the workers' interests, not based on true the legitimacy, the mission of the centres and the exercise of the profession. Finding the balance between the patients' needs, efficiency and excellence in the services and personalised treatment is a core challenge.

CONCLUSIONS

We must recall that, just as people deserve respect for their physical and moral integrity and have their different dimensions, we must not only ensure that they eat, drink, bathe and take their medication, rather their interaction, their relationship with their caregivers, with the centre staff and with their family is also crucially important. Beyond reason, they have dignity and deserve the utmost respect, the utmost attention, and this means dignifying their dependence.

The way a society treats its disabled members says a great deal about its solidarity. And recalling J. Rawls and his veil of ignorance (Rawls, 1995), everyone, if unaware of their biological-social lottery, would choose to live in a fair, socially conscious society rather than a *random* society. In the former, the most fortunate ones in the biological-social lottery have to help minimise the disadvantages of the less fortunate ones in that lottery. In contrast, in a random society the law of the jungle prevails, animal law, and in this kind of society it is meaningless to speak about ethics or human dignity; in it, the disabled are excluded through simple *natural selection*.

The incidence of luck in a person is inversely proportion to the level of justice in the society in which one lives; it is *bad luck* to be disabled, but it would be even more unjust for this random issue to condemn the disabled person to undignified treatment. We must keep fighting on behalf of individuals with serious intellectual disabilities in order to ensure that they do not lose too many degrees of interaction; we must continue to encourage them to fight for life because it is worth it, despite their condition; we must fight against *diagnostitis* and determinisms that dictate that if one cannot live a normal life and function normally in society, life is no longer worth it. As long as there is someone who makes them feel, in their own way, that they are worthy and will *find* their quality. Frankl said it best: "whoever finds a *why* can handle any *how*. A society that

treats disabled people as worthy is giving them a *why* so that among all of us (they are dependent) we can discover how to do it” (Frankl, 1980).

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