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Ethics in care services for people with severe mental disability

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SUMMARY

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INTRODUCTION

Respect for the dignity of people in care settings is based on the following principles:

- Accepting the service user as an autonomous being with freedom of conscience and control over his or her own life and health (*autonomy*).
- Doing everything possible to achieve benefits and to prevent harm: in other words, considering the risk-benefit balance of any intervention (beneficence vs. non-maleficence).
- Not discriminating for reasons of race, sex, age, class, etc. but instead on the basis of greatest need (*justice*).

These are the three guiding principles[1] of universal ethics, which constitutes a form of commitment, developed only in recent years, which transcends culture, ideology and beliefs. These are the principles of an ethics which is universal and inclusive, but also possible, and which, in so far as its application may give rise to conflicts of values, helps make us aware of the work which care professionals perform and point a way towards the resolution of such conflicts.

To varying degrees, a defining characteristic of people with mental disability is their vulnerability with respect to the challenges of their lives, be these biological, psychological or social.

Let us consider these two issues in a little more detail: respect for the dignity of the individual, and the principle of vulnerability.

The first and most fundamental ethical principle is that of the dignity of the individual. From the Latin *dignus*, it means "worthy" and refers to the intrinsic value which each and every human being possesses, irrespective of his or her economic or cultural situation, beliefs or ideology. Independently of his or her health, capacity for autonomy or even his or her moral condition.

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[1] Beauchamp, T. L.; McCullough, L. B. *Ética médica*. Madrid: Labor, 1987.

This intrinsic value is based on the capacity – whether full or reduced – of people to regulate their behaviour on the basis of their own standards (autonomy); that is, on the basis of being emancipated with regard to their surroundings, the possibility of constructing a biography. An individual does not consist solely of what he or she is, but also of his or her aspirations, both public and private. And this is always a personal project. Every human life can be more than just life; it can be a life with meaning, a biography. Being a person is the fundamental issue, and it transcends any individual condition such as disability. Severe mental disability imposes huge limitations on this project of personal construction, and may even render it impossible. In her paper, Dr Begoña Román refers to two definitions of dignity. “The first, in its loose sense, is common to all people insofar as each person is an end in themselves (an absolute value, the source of all other values). Each person has the potential to develop their autonomy but, in some cases, is prevented by a condition which affects mental development and consequently the autonomous capacity to attain dignity in the strict sense of the word.”[2] Dignity in the strict sense is the true object of any moral endeavour which requires the development of personal autonomy in order to think for ourselves and live in a coherent fashion.”

So much for our description of the value of dignity. How does all of this affect us? A prescriptive approach might lead us to conclude that everyone has dignity and deserves our respect simply as a result of having being born. Everyone deserves respect, regardless of what he or she is like. I recognise, then, the other’s difference, and I accept and respect it. In this recognition of the other, in the defence of his or her dignity, we also affirm our own virtue and dignity. As a result, that dignity which distinguishes us from other animals also makes us more responsible. As Dr Román has noted, “Those of us who interact with them put our own dignity on the line with the treatment we offer to others if we forget that, regardless of whatever disability they may have, they are first and foremost people.”

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[2] Román, B.; Gutiérrez, A. “Dignidad y respeto. Un intento de fundamentación formal.” In: Murillo, I. (ed.). *Ciencia y hombre*. Madrid: Ediciones Diálogo Filosófico, 2008, p. 427-434.

The principle of vulnerability (Kemp and Dahl Rendtorff, 2000)[3], express two key ideas. The first is the finite and fragile nature of human existence. From this perspective, every human being is inherently vulnerable, exposed to hurt, illness, failure and death. As a result, vulnerability is not restricted to certain individuals but is, instead, a universal principle applicable to all human beings. Vulnerability is, in the first place, an essential element in the organisation of the health development of individuals and indeed of the whole human race. Without the extreme fragility of human babies it would be impossible to account for the extraordinary process of interdependence which is essential for psychobiological development and growth. However, the type and degree of vulnerability, like disability, vary both from one person to another and during the lifetime of any given individual.

The second idea to be deduced from the principle of vulnerability is also of a prescriptive nature. Vulnerability is the object of any ethical principle and is also the basis for an imperative of moral responsibility. As human beings, we cannot remain indifferent to the vulnerability of others, but must instead respond responsibly to their appeal. This means we must be sensitive to the fragility of others, and create mechanisms to address their vulnerability. We therefore need to ensure that we compensate for this lack of biological, economic, interpersonal or social opportunities, if necessary including strategies of positive discrimination.

This must provide the foundation upon which we build, day by day and moment by moment, an *ethics* of caring (a caring which is based on values) for people with severe mental disability. Both Begoña Román and Pablo Hernando agree that this must be a civic ethics, quite different from the older compassionate values based on religious sentiment, and also clearly distinguished from old-fashioned paternalisms (*moral obsolescences*, as Román puts it), based on the principle of justice (on the rights of individuals), and which encompasses every aspect of our care activity: the definition and pri-

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[3] Rendtorff, J. D.; Kemp, P. *Report to the European Commission of the BIOMED II Project “Basic Ethical Principles in Bioethics and Biolaw.”* Vol. II. Ed. Centre for Ethics and Law (Copenhagen), Institut Borja de Bioètica (Barcelona), 2000.

oritisation of public policy (macro-management), the organisation of services (meso-management) and specific professional intervention (micro-management).

And we also need an ethics of organisations. In the two presentations which provided the basis for the discussion and in the discussion session itself, the importance attached to this issue by participants was clear.

Our service users, including their relatives, often live in situations of mental and behavioural disorganisation, and require both dedication and very high staff numbers (levels of technology in our sector are still very low). Ensuring individualised care not only requires far higher numbers of care professionals, but also demands that these professionals are of the very highest quality. This in itself constitutes a massive challenge, because care staff are neither valued nor rewarded financially in our society.

So what organisations do we need? In today's world, to direct a company is to create an environment. And this means promoting conditions for participation and debate, stimulating criticism so that new proposals arise, using credibility and tact (sincerity, leading by example, ethical values). Albert Schweitzer said, "Example is not the main thing in influencing others. It is the only thing." In organisations, it is often the case that the more uncertainty there is, the more people respond by defending the way things have been done in the past, the stronger their need to cling to old beliefs, rejecting new insights or knowledge. Or, as Keynes said, "The biggest problem is not to let people accept new ideas, but to let them forget the old ones." In organisations which are buffeted by internal change and external threats, uncertainty can lead to a strengthening of rules, regulations, hierarchy and traditional standards of behaviour.[4]

Recognising the imperfection of organisations, and their fragility, is incredibly stimulating and helps to inoculate us against complacency. It makes us more receptive to the claims of our stakeholders (José Aguilar, in J. Fernández

Aguado, 2008)[5]: service users, families, care professionals, other services, the authorities, and wider society.

For this reason, it is useful to consider the specific mission and institutional values of our organisations, and to adapt them whenever necessary.

It is not so long since we moved away from all-encompassing institutions, where care practice was often mixed with segregation or even the simple repression of behaviours deemed abnormal or unacceptable.

Although we now tend to think of this is as a problem of the past, it is far from clear that such ideological prejudices (or values) are no longer expressed in care practice. We need to be particularly cautious in organisations such as ours which provide global care for the person with a disability, either because this person needs support across the different areas of their life or because the organisation itself is responsible for providing all the services needed: education, housing, work, therapy, leisure and social life.

As a result we run a real risk of reducing the multiple aspects and identities of the individual to a single one which we have imposed upon them: that of disability.

Distinguishing between responsibilities and roles in each of the different aspects of the service we are offering, preserving the independence of the guardian, the family, the monitor or the psychologist, accepting differences and conflicts, ensures that we accept the complexity of the person being cared for, and that this individual has more space to construct a personal project, even if this is often limited to obtaining positive sensations of pleasure, love, security or well-being. We must discuss as often as is necessary and possible the *value-based care model* which we offer to our users who suffer from severe mental disability: how we treat their privacy and the relationship between this and safety, how we accept their sexuality or educate them in this regard, the meaning of self-determination, how far we should go in applying the principle of normalisation, and how to resolve the conflict between standardisation

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[4] Merry, U.; Kassavin, N. *Coping with uncertainty: Insights from the new sciences of chaos, self organisation and complexity*. Westport: CT. Praeger Publishers, 1995.

[5] Quoted in Fernández Aguado, J.; Urarte, M.; Alcaide, F. *Patologías en las organizaciones*. Madrid: LID Editorial, 2008.

and individualisation. As we will see, these concerns, together with an awareness of our own limitations (or what one might call our *disability*) in helping others, together with questions such as how to improve our organisations and the quality of our care professionals, provide the focus for much of the debate.

The next question is to identify the tools which can help us to bring about change in our organisations. Pablo Hernando, in his presentation, reviews the current situation regarding healthcare ethics committees in health settings, and argues that these bodies should be included in centres' quality policies, instead of being treated as separate instruments for the general strategies of the organisation. A healthcare ethics committee is, in the words of Hernando, an "interdisciplinary advisory committee set up to analyse and advise on ethical conflict in healthcare institutions with a view to contributing to improved healthcare for patients".[6]

Both in his presentation and in the contributions to the discussion, we heard about a range of experiences relating to the question of which instruments or strategies for promoting change and improving institutions were best suited to ensuring that organisations are better at making professional practice reflect the values we seek to defend: codes of ethics, good practice manuals, training in values for professionals, action protocols, and others.

This is clearly an issue to which we will return. It seems likely that the fundamental issue is not that of which instrument we should use, but rather that each organisation must identify specific strategies for translating its mission into reality, and for implementing in its daily practice, in the hope that, in the words of Frankl[7], a man who "knows the 'why' for his existence ... will be able to bear almost any 'how'."

It is to the credit of the Víctor Grífols i Lucas Foundation that it is has focused on a sector and on a group of professionals who, while often ignored by society as a whole, are guided by a genuine sense of vocation and mission, of moral conscience and duty. If one thing emerges from the pages of this publication it is this.[8] We hope that this document helps them in their mission, that it stimulates new questions which enable care professionals to continue to respond to the fresh challenges they face.

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[6] Corporació Sanitària Parc Taulí. *Reglamento interno del CEA*.

[7] Frankl, V. *El hombre en busca de sentido*. Barcelona: Herder, 1980.

[8] Cortina, A. "Universalizar la aristocracia. Por una ética de las profesiones". In: *La bioética, lugar de encuentro*. II Congreso Nacional de la Asociación de Bioética Fundamental y Clínica. Barcelona 1998.

The ethics of caring for people with severe mental disability

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1. Introduction

The purpose of this article is to address the importance of ethics in caring for people with severe mental disability. With this in mind, I shall begin by defining the terms which appear in the title of this paper.

Ethics we understand to mean a critical and rational reflection on the customs and habits informed by our morals (mos-moris). The purpose of this reflection is to decide, with as much objective distance as possible, whether the moral responses that have hereto guided our behaviour have become obsolete (perhaps they arose from the values and knowledge of a specific historical context) or whether they are still valid, and if so, why? The moral question resides in what we should do, whereas the ethical question asks why should we do it. The value of ethical debate, and we should expect no less, is that it allows us to develop the most appropriate ways (habits, customs, values) of tackling the issues we meet in daily life, on questions which depend on us and which are within our reach.

A *service* is an interpersonal relationship in which one party 'does something' for the other. A service differs from a mere product because the quality of the service depends on the quality of the interpersonal relationship. A care service attends to the needs of people. Kant reminds us that objects have a price but persons have dignity. The German word *Achtung* means both 'attention' and 'respect'; 'attention' can also mean 'to take care' (as in the Spanish *servicios de atención*) as well as 'being mindful of others'. 'Respect', from the Latin *respicere*, means 'attentive gaze'.[1]

Autonomy means 'self-determination'. According to Kant, who promoted the notion of '*autonomy*' in the moral sphere, our dignity springs from our capacity for self-determination, our autonomy.[2] This paper, however, deals precisely with those people who are in care (deserving of our care and attention) who have dignity but lack autonomy, having never enjoyed it and being unlikely to do so in the future. This paper deals with people with *severe mental disability*. When our disability is intellectual, our autonomy is impaired because the first condition for self-determination resides in our capacity to understand the world and make reasoned informed choices, free from obstacles and controlling influences (internal and/or external) and consistent with our own set of values.[3]

There are always degrees to a person's autonomy. Most people can determine what they do to a greater or lesser extent. The people who are the subject of this paper have severely reduced or no autonomy precisely because of the nature of their disability. Their lack of power to determine their lives resides in their inability to think for themselves and, consequently, to live for themselves. These are not the partially disabled, able to carry out some functions for themselves. These are the severely mentally disabled, whose disability is the result of a pathological process which is not only irreversible but, in many cases, degenerative.

This, however, according to Kant, does not diminish a person's dignity. It is important that we reflect on the ethics of caring for the severely mentally disabled, precisely because they are human beings. Let us consider two definitions of dignity. The first, in its loose sense, is common to all people insofar as each person is an end in themselves (an absolute value, the source of all other values). Each person has the potential to develop their autonomy but, in some cases, is prevented from doing so by a disease which affects mental development and consequently the autonomous capacity to attain dignity in the strict sense of the word.[4] Dignity *in the strict sense* of the word is that attained by the person, the true object of any moral task and requires a person to develop their autonomous capacity by degrees until they arrive at the ability to think for themselves and live accordingly.

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[1] Vid. Esquirol, J. M. *El respeto o la mirada atenta*. Barcelona: Anthropos, 2006, p. 65.

[2] Kant, I. *Fundamentación de la metafísica de las costumbres*. Madrid: Alianza Editorial, 2000.

[3] Beauchamps, T. L.; Childress, J. *Principios de ética biomédica*. Barcelona: Madrid, [etc.]: Masson, 1999.

[4] Román, B.; Gutiérrez, A. "Dignidad y respeto. Un intento de fundamentación formal". In: Murillo, I. (ed.). *Ciencia y hombre*. Madrid: Ediciones Diálogo Filosófico, 2008, p. 427-434.

Thus, all people possess basic human dignity, from the perverse murderer to the anencephalic baby, but neither the murderer nor the baby are in possession of dignity in the strict sense of the word. The former has lost his dignity by abusing his autonomous capacity[5] and the latter can never claim it. And in our dealings with them, our own dignity is at stake if we forget that, despite the immorality of the murderer and the helplessness of the baby, they are and always will be human beings.

1. Why pose the question now?

1.1. Changes

Our need to question the ethics of our care services for the severely mentally disabled today is simply a result of changes in society which have forced us to review our traditional care models. New issues are continually being encountered and these need to be addressed. Let us analyse some of these changes.

Changes in medicine

In the last 30 years, the practice of medicine has seen more change than ever before. Under the bright umbrella of progress, all changes are assumed to be for the better, to represent a step forward. Modern medicine has awakened in many people exaggerated expectations of its power, expectations which are often disappointed. So, for instance, medicine has greatly enhanced our ability to diagnose disease, but this has not been matched by our ability to treat it: we might know what we have but do not know how to cure it.

In the case of the severely mentally disabled we may know about the condition and have a diagnosis but, in the absence of a cure, the most appropriate treatment where no medical attention is necessary is the delivery of lifelong care. The type of care required and deserved goes beyond the strictly medical and must be provided in the context of social and public health. Doctors, psychologists, physiotherapists and social workers must work together with centre staff (often non-professionals who spend the longest with the patient) and provide care as a team based on interdisciplinary support.

The changing nature of disease

Thanks to scientific progress, technology, rising incomes and the welfare state, the life-expectancy of the mentally ill has increased, and many are living into old age. The same applies to people with mental disabilities, particularly now that social rejection, family apathy and healthcare neglect are being overcome. Longevity in such patients, however, is linked to other disease, such as Alzheimer's, from which there is no prospect of recovery. The result is that an increasing number of patients are becoming heavily dependent on long-term medical and social care. It is because of these changes that I see the need to update Spanish legislation (such as the Law for the Promotion of Personal Autonomy and Care of Dependent People) and to provide new care centres able to cope with a range of new diseases and disabilities while continuing to care for patients with traditional diseases who are now living longer.

Social change

A major change to traditional care models has resulted from women entering the workplace. The severely mentally disabled are no longer always able to be looked after at home. Increasingly, families are handing over responsibility to care centres. Indeed, the very notion of 'family' has become more complex.

Multiculturalism has also thrown up a number of questions. Traditionally, care centres have brought together people from different social backgrounds, but not different cultures. Now, as multiculturalism 'arrives' at care centres, not only via patients and their families but through the professionals and carers, we are finding the need to define the values which lie behind our working practices, because they are not necessarily based on shared sensibilities. What do we understand by quality, what are 'normal' hygiene standards, what constitutes a 'normal' meal or 'normal' levels of privacy? These social changes make the delivery of care across all areas more complex.

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[5] Camps, V. "La paradoja de la dignidad humana". *Bioètica i Debat*, n.º 50 (2006), Institut Borja de Bioètica, p. 6-9.

Long-term residents

People who suffer a severe mental disability from which there is no prospect of recovery, are often taken to care centres where they will live for the rest of their lives. These care centres eventually become their 'home', and as long-term residents they are treated and cared for in a special way. A long-term resident's circumstances are very different to those of a patient staying in a hospital or care centre for a short, medium or even long-term stay, because the patient knows the arrangement here is temporary.

Because the severely mentally disabled are long-term residents, we must look again at what type of lifelong care, beyond the purely medical, we are offering and based on what care models. The care model should be highly personalised, for it is important that long-term residents feel totally 'at home'.

These days, standards of care for long-term residents are judged less on the accuracy of the original diagnosis and more on the level of care provided: that is, the service as perceived by the patient and the family, who are ultimately responsible for decision-making on their behalf. The relationships developed between care staff and severely mentally disabled patients and their families will often be very different to relationships developed in other types of centre.

1.2. Moral obsolescence

Yes, we must adapt to these external forces of change, but let us not forget that we too can provoke change, when our normal patterns of behaviour and our morals become obsolete. It is from the standpoint of justice, not Christian charity or Hippocratic beneficence, that care should be delivered to people with mental disability.

Charity and beneficence

Traditionally, it was religious orders or the benevolent professional classes that decided on the type of service or care to be given in accordance with their religious morality or altruistic beliefs. But should the delivery of care really be left to religious groups, to their charity, to mercy, to compassion, to a discourse based on religious choices and personal maxims? In my view, examining the ethical questions surrounding the care of the disabled should be our *primary concern*. Changing the order of importance alters the result: we now have civic ethics and, therefore, *the right* to healthcare. It is from a desire to be fair and in recognition of the value of personal dignity, that we should be providing care services to the mentally disabled, according to minimum ethical standards.

Paternalism and the well-meaning

Alongside the care administered by religious groups was that provided by the paternalists and the well-meaning, without the consent of the affected (within their limited capacity) or their family. Good intentions were considered sufficient grounds despite the saying 'the road to hell is paved with good intentions'. Paternalism would often lead to overprotection and the displacement of the family which, despite the best intentions, became a sort of enlightened despotism: Everything for the people, nothing by the people.

Justice requires there to be informed consent from a position of symmetry. Clearly, the severely mentally disabled cannot do this, but nonetheless, they should always remain the subject of our attention, not just the object of our care and protection.

Ignorance and vulnerability

Often, it was families themselves, not knowing how best to deal with their disabled relatives, who most contributed to their vulnerability. This was done in one of two completely different ways. Firstly, it was not uncommon to 'hide away' family members considered 'abnormal', keeping them apart, behind closed doors, reducing them to a mere vegetative existence, discouraging interaction with others, in this way further contributing to their isolation and disability. Perhaps the intention was well-meaning, aimed to prevent suffering in others. Later this practice was to be reversed by 'normalisation'.

And so, at other times, families embraced 'normalisation' in an effort to ensure the mentally disabled be normalised and accepted into society. One instance of this was the immersion of mentally disabled children in mainstream schools and later as workers in 'willing' companies (even supposedly profit-making ones). The problem then resided in the negation of their differences and their disabilities. They were afforded equal status and dealt out equal treatment. Excessive normalisation, again, failed to take into account the divide between the mentally disabled and the rest of society for whom 'the norm' is to live by self-determination and with a degree of self-sufficiency.

As the mother of a girl with Rett Syndrome reminds us in her book *Criatures d'un altre planeta* (Creatures from Another Planet)[6], disabled children can suffer frequent convulsions. A normal school environment is good neither for them (if schools are not equipped to respond to seizures lives could be put at risk) nor for their peers (who are denied lessons 'as normal'). What can 'normalisation' actually mean for people who are completely dependent on some form of care? According to the psychiatrist Josep Ramos, imposing mainstream life upon the mentally disabled negates their personal limitations and risks exposing them to excessive frustration and failure. Is dependency 'normal'? The answer is no, but failing to acknowledge a person's dependency in an attempt to make them 'normal' is a form of denial.

The mentally disabled cannot expect to have the same rights and certainly not the same obligations as the rest of society. They are deserving of a different set of rights, more specific rights, based on their differences. It is precisely when we accept that the mentally disabled cannot care for themselves that we are forced to reconsider what the most appropriate forms of care are, those that are respectful of personal dignity and encourage well-being, always mindful of the differences between the 'able' and the 'dependent'. Dependency should not be a shameful condition but simply one that merits (is worthy of) special attention. Because the truth is that the mentally disabled are special and so should be their education, their workplace, their treatment and their environment.

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[6] Pedrosa, E. *Criatures d'un altre planeta*. Barcelona: Dèria Editors, 2008.

2. What ethics?

2.1. Ethics as critical reflection and rational dialogue

Given that we know that our morals can become obsolete and that science will continue to expand our knowledge and change the way we treat each other, it is important we nurture the habit of continually scrutinising our customs and habits, since we can only suspect that our daily lives, as Gadamer reminds us, are plagued with inevitable prejudice.

Habits, customs and debate

Over and above morals, we need ethical standards to help us renew our customs and habits, the morals of today, which in the future will almost certainly be obsolete. By influencing our moral behaviour, our ethics (moral thinking) can guide decision-making in morally pluralistic societies. This is achieved through dialogue, deliberation and inter-and trans-disciplinary debate. It is essential here to put rational discourse and debate –the giving of reasons, the defining of the 'why'– above our habits and customs. To paraphrase Frankl and Nietzsche, he who has a why can bear almost any how.

Truth and justice

This civic ethics is based on two ideas. One is cognitivism, based on fact, validated knowledge and empirical proof; on evidence we hold in the here and now. The other is justice, understood as fair treatment between consenting parties where limited resources must be shared. We cannot make just decisions without factual knowledge, based on science. But, in order to access this knowledge and digest it we must be guaranteed the right to reliable information, to education, the freedom of investigation and expression, to ensure we can freely consent.

Good according to whom?

Civic ethics is there to serve truth and justice, and is neutral to the individual's worldview, their definition of quality of life and what is 'good'. Its purpose is to defend impartiality and pluralism, achievable only if all stakeholders work together, be they service users or providers. So patients, families, professionals (medical and carers), healthcare organisations, the government and society in general must be able to communicate clearly, and each party must know its role. Essential too is a consensus on the definition of human dignity and the rights to which we are entitled according to our capacity (personal and social), on which to later base a variety of notions of quality of life and of what constitutes 'goodness'.

2.2. Ethics and justice

We need to promote civic ethics as a means of upholding our basic human rights. This is the substance of justice. These rights are our basic entitlements on which depend our ability to seek further, preferential rights. Our rights are the minimum entitlements which any person should be guaranteed to enjoy a certain dignity of life through which to choose their quality of life. And as mentioned above, the incapacitated and dependent need other priority entitlements, a different 'set of rights'.

With the consent of the affected parties

In effect, civic ethics transcends cultural differences and aspires to the universal. Its basic content is rights and its method is deliberation and dialogue. The outcome of a decision is considered fair if it has been agreed by all affected parties, who give their consent based on an informed choice and from a position of symmetry.[7] Justice needs procedures if it is to be the subject of its own enquiry, it requires a methodology based on dialogue and deliberation. Thus, it is necessary to organise dialogue and debate based on some guaranteed basic rights.

This paper, however, deals with those cases where the people most affected by the decisions being made, on so many aspects of their lives, are unable to participate in the decision-making process. For this reason, we must appeal to solidarity as the necessary complement to justice, because those affected by our decisions are unable to make their own informed choices as equals.

Ethics, here, could be looked at on three different levels: firstly, on the *macro* level of healthcare policy and social service legislation. Secondly, on the *meso* level of care centres themselves and finally, on a *micro* level, the relationship between the professional and the patient, or as in our case, the service user together with the family or guardian.

Bearing this in mind, the following questions are essential if we are to uphold ethical justice and solidarity in caring for the severely mentally disabled:

1) To what rights are the severely mentally disabled entitled?
2) This question concerns our duty to protect their dignity of life and is about minimum civil standards.
3) What are the preferences of the severely mentally disabled patient and their family? This question addresses with the desired personal worldview of the family and requires careful observation of the patient to identify what factors contribute to their well-being and comfort.

What options are available to care centres and care professionals enabling them to respond to the needs above? Are these options helped or hindered by government and society? This question relates to the ethics of professional and care centre responsibility and touches on public healthcare policies and the social models to which we aspire.

Dignity and vulnerability

As a minimum civil standard, we should ensure we provide decent living conditions for those with limited capacity to express their needs, make requests or demand answers. The rights of the incapacitated are necessarily different to those of society in general. In this case, the right to education does not mean the right to mainstream schooling but instead an entitlement to the kind of education that can develop a degree of capacity within the person's overall disability.

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[7] Habermas, J. *Aclaraciones a la ética del discurso*. Madrid: Trotta, 2000.

The source of practically all our entitlements is our right to self-determination, to freedom or autonomy. The people we are dealing with in this paper need our constant, permanent and considerable support as people. Their principal entitlement is personalised care which guarantees their dignity.

Quality of life

A just life should give us the freedom to seek out a better quality of life. Because the disabled depend on other people, it is up to health professionals, organisations and families to do this on their behalf. We must find the time and means to improve the well-being of the disabled. This, as we will see below, will depend on a person's ethical approach, willingness and availability.

Responsible citizens

As citizens we are responsible for the place that the mentally disabled occupy in our society. We are responsible for the image we portray of them, the environment we create for them and the treatment we provide for them. The mentally disabled are people with a very low capacity for self-determination for two reasons: firstly, because of the nature of their disability and secondly, because being a resident in a care centre inevitably compromises your individuality, even when the organisation upholds your dignity and rights to quality of life. As institutions, care centres must cater not only to individual needs but to those of other residents, members of staff and accompanying families too. It is up to us, as citizens, to manage pluralism and diversity by upholding minimum civil standards. And the degree of our responsibility should be proportional to our capacity and knowledge.

2.3. Professional and organisational ethics

Professionals in the social services cannot go it alone, and nor can other stakeholders manage without them. Leaving the ethical questions on caring for the dependent and encouraging autonomy to them alone is demoralising for professionals and condemns them to a contradictory situation in which they want to succeed but cannot. It is essential that professional responsibility goes hand in hand with organisational and institutional responsibility, supported by professional associations within the wider context of social policy.

How do we enhance the quality of care?

In the context of professional care ethics, quality as an end legitimises the means. So what do we understand by this? Quality comes from satisfied expectations which are ultimately related to well-being and/or just actions.

In order to experience 'quality' our expectations must be satisfied. Expectations are appropriate if they are based on scientific evidence (are they realistic?); if they comply with the minimum standards enshrined in our rights and obligations (are they just?) and, last but not least, whether they bring happiness or not (are they good or bad?). In effect, the perceived quality of a professional service depends on patient satisfaction, but since knowledge of legislation and new research in the field is largely exclusive to members of the profession, and users can be misinformed, we ultimately depend on the professionals to maintain high standards of practice.

A number of factors constitute quality: user satisfaction, professional skill and knowledge, professional evaluation of the service they deliver, new research in the field, the options available to the organisation depending on its resources, efficiency achieved and so on. Care professionals should be up to date on their areas of expertise (aware of new legislation and therapies for instance) and should be a reliable source of information on these topics if they are to do justice to patients and their families.

Politicians are often guilty of creating unrealistic expectations among voters (take for instance the aforementioned Law for the Promotion of Personal Autonomy) which in practice cannot be satisfied by care workers because of shortfalls in human and technical resources. In addition to the pressures at work, care staff have their own personal commitments to honour: mortgages, school fees and insurance premiums to pay. Like any other employee, they must toe the line and get on with their job, coping face-to-face with dissatisfied service users and families every day.

Care organisations should be responsible for professionalising their carers. Generally speaking, the staff who spend most time with patients are the least 'qualified'. It is important that they are made to feel 'professional' and responsible for the care service they deliver to patients on behalf of the organisation. This can be achieved through recognising the value of the job they do and raising its status from that of merely 'paid work'.

Healthcare professionals risk losing their credibility and that of the profession because the provision of services relies on trust, the moral capital on which all interpersonal relationships are based. Healthcare professionals are directly responsible for improving the life conditions of the mentally disabled and, indirectly, for ensuring that justice prevails. So it is that they are responsible not only for implementing legislation within the care context, preventing negligence and for promoting the well-being of the patient, but also for ensuring that new or greater dependency is not created with regard to the organisation or staff, professional or otherwise. The care organisation must take care, by upholding the principles of beneficence and non-maleficence, that a person's condition is not exacerbated by the disorientation resulting from arbitrary treatment and increased dependency. So, for example, an occasion arises when, for the sake of efficiency or to save a little time (or perhaps in an act of misguided helpfulness), we might do a patient's buttons up for them where they used to do it by themselves. After a short while of not doing up their own buttons, a new dependency has been created.

How do we enhance organisational quality?

The ethics of any organisation are legitimised if the quality of the service provided is good. But the picture is complex given the number of professions involved, an even greater number of individuals and users in different neighbourhoods and regions, and changing economic contexts. The role of the professionals here is crucial and we must support them in their task: organisational ethics are crucial to defining care models which provide consistent guidance on management issues and on how to deal with family requests.

The organisation is an important moral agent. In forging a good organisational ethics the following factors must be borne in mind:

a) Favouring a *corporate ethos* over the individual approach. An ethos defines an organisation's goals and how they are to be achieved; it is the special way of working and thinking which distinguishes it from other organisations. An organisation's corporate ethos would also define the care model and standards shared by all employees. A corporate ethos would offer clear guidance on an organisation's overall approach to long-term care of the incapacitated.
b) A *code of ethics* (with its own committee) would set out the organisation's values and define the types of action and procedures which the organisation expects from it staff. As a code of ethics it should not be mistaken for the centre's rules of procedure. A code of ethics would encourage educational programmes, empowerment (responsibility is proportional to power) and the care not only of patients but of all staff working at a centre. By and large, values between centres will be similar, but it is just as important that they are set down and agreed by each centre, bearing in mind their specific mission, the management resources available and the collective will to implement. When there is collective agreement within a care centre over the hows and whys of best practice, the mechanisms for implementation begin to emerge.
c) Generate a *participatory democracy*. Discussion forums should be set up to encourage participation and debate. In these forums, conflicting ideas should be considered a sign of creativity and willingness to change and improve.

Consistency and family values

It should not be forgotten that when we talk about consistency of practice we are not referring only to results or consequences. There must be a consistent approach in each of the following three areas: mission and values; actions and procedures, and consequences and impacts. For instance, although a family in the care centre may be very happy with the service they receive, if this is a result of preferential treatment because of who they are or what they represent then this action would not be consistent with the ethos of treating all patients in an impartial and just manner. Maintaining a consistent approach is a challenge when values and worldviews differ between families and standardised treatment becomes impossible.

3. Why do we need ethics for organisations and professionals?

3.1. Awareness of consistency and belonging

The only real way of implementing professional and organisational ethics is to ensure they are shared by the individuals who make up the organisation. In order to achieve this, professionals must share a sense of pride in being a part of it. Professionals represent and project the public image of the organisation. They are its visible face and exert a major influence on how and in which direction it is moving.

It is not difficult to ascertain the level of professional commitment of an employee to an organisation. Simple questions of the type What does the organisation expect from you that you like? What does the organisation expect from you that you do not like? What doesn't the organisation expect from you which you would like it to? The answers can provide information on whether the professional ethics of your employees are in line with those of the organisation. We could also ask these questions to service users, in this case, the families of the severely mentally disabled people in our care.

The great enemy of ethics is complacency. We apply ethics in order to improve our lives not because of a desire to satisfy personal vanity. Since all humans are fallible, organisations must be prepared to manage their ethical learning by building on what we get right, learning from mistakes and analysing inconsistencies.

Professional training in values and communication skills

Why the need for professional and organisational ethics? The answer is that although most professionals have had some degree of professional training, very few have studied values and even less had the organisation's values, so important to professional practice, clearly explained to them. In professional practice and in serving the public, good intentions or the desire for self-realisation are not enough. We must also be aware of who we are offering the service to and provide personalised treatment on that basis. And our 'shared sensibilities' are of no use if they are based on underlying traditions that vary depending on origin. We also need to stay flexible as our professional goals develop and change.

Given that ethics is fundamentally based on discourse, we should work to improve communication skills amongst professionals as well as in professional-family, professional-patient and professional-organisation relationships. It is inconsistent and arbitrary, moreover, that night and weekend shifts have to conform to different rules than day shifts. Unfairness generates distrust. We ask ourselves the question: why are professional and organisational ethics necessary? Simply put, it is a question of justice, solidarity, quality and trust.

3.2. The relationship with the family

The family is directly responsible for the service user's well-being and we, the professionals and organisations, should keep them informed on the condition of the person whom they have entrusted to our care.

Autonomy: respecting idiosyncrasies

Because the family is the legal representative of the patient, they must consent to a large part of the care services provided by the centre. The care centre should always seek to sympathise with the family's views and particular habits in an effort to accommodate pluralism and respect a family's individuality. We must ensure, however, that the safety and dignity of the patient is not compromised.

Communication: informing about therapies, diagnosis and courses of action

In cases where service users are taken home for a few days, the family assumes responsibility for continuing to provide treatment and administer medication as well as taking all precautionary measures to ensure the individual's personal safety. The professionals must give the family clear instructions where this is necessary.

Organisation and family: guidance on mutual expectations

As discussed above, if we want our care to be considered 'quality care', we must satisfy family expectations. In order to satisfy expectations, we first have to identify them and hope that by informing families correctly, these expectations will be 'reasonable'. At the end of the day, however, a professional is responsible for the quality of the care they deliver regardless of family satisfaction. After all, families can be inexpert and misinformed, or over-informed and over-demanding. Professionals play a crucial role in educating families and guiding them through reports, opinions, new and amended laws and the correct use of medical equipment, without which families would be at a loss on what to do and what to expect.

Rights and obligations, understanding and empathy

Families also have rights and obligations. As individuals, members of the family unit are responsible for fulfilling their own obligations in relation to their own particular needs and those of the service user. So, having the right to visit their loved one creates an obligation to do so. It is not just a question of "I have rights and others have obligations". Having the right to education also implies an obligation to educate oneself, and does not imply that others have the obligation to educate me. In the same way, the right to take decisions on behalf of a severely disabled family member implies an obligation to take on some of the responsibility for upholding their dignity and quality of life, and since interpersonal relationships are essential to a patient's quality of life, the family has a large part to play.

3.3. The relationship with the patient

The patient is the reason that care services exist. Severely mentally disabled individuals are chronic, often lifelong patients, for whom the centres become home. Thus, it is essential to understand the importance of the space inhabited by a patient and dedicate time to it. Quality care implies valuing a patient, their circumstances and their surroundings. Surroundings can be very influential in quality of life. Firstly, we must understand that our surroundings are not just our space. Our surroundings can recognise us, nurture us, personalise us, welcome us. Our surroundings can also be impersonal, creating a sort of 'non-place'. We must be wary of creating a space which dwells on the disease or which labels people as violent or aggressive and gives up on them.

With respect to time spent with patients, we should be able to find enough time in which to observe them, get to know them and develop a relationship with them. It is ethically unacceptable to say we do not have time to reflect on our care model, on the quality of our service or how time is spent with patients. If we should be doing so, we should *be able to* do so. It is important, then, that we reflect on how patients spend their time, whether there is enough variety of activities. Are they allocated enough time on activities in relation to the pleasure they get out of them? If, for instance, we observe a patient to be particularly fond of showers, why not prolong it and extend the feeling of well-being? Let us now turn to interpersonal relationships and how these should be established.

Being careful and tactful

The human dimension of a patient must never be forgotten. Patients always respond to some degree to their surroundings –they are not in a full vegetative state. The patient should be treated as a person and, therefore, be the subject of our attention, not subjected to it, but instead the protagonist. Our approach could make the difference between a patient feeling like a passive consumer of the homogenised care provided by the centre and a patient feeling (using their presence and communicative abilities however small) that the services are designed for them. Despite their disabilities, patients often find ways of making themselves understood and, however limited, can express pleasure, displeasure, satisfaction, affection and discomfort.

Interaction and sociability

The most impersonalising influence is lack of communication. This is why all punishment is often based on exclusion or confinement and putting up barriers to human contact. We often ignore people who do not understand us, because they do not speak or act. By treating people impersonally, we degrade ourselves. As Serra very rightly says, through our treatment of the 'quiet' we will know ourselves.[8] We must enhance a patient's interaction and sociability in new ways (our own ways are too rational and verbal) by adopting an open approach in order to interpret what patients are telling us.

The severely mental disabled often talk to us using their eyes, with smiles or simply by touch. It is important that we help to draw out meaning where questions are not directly asked. It is often the case that the more dependent a patient, the less demanding they are. And it is up to us to interpret their gestures, if we are to anticipate needs. Treat those who are equal equally and those who are unequal unequally, according to the Aristotelian principles of justice.

Be attentive: watching and listening

We mentioned above how in order to respect a person's dignity, in the way we all deserve, we must first be attentive to them. In our particular case, we must develop our attention in specific ways. We must try to find out what a particular patient is trying to tell us with that look or that noise. And here we face an unavoidable challenge – how to ensure we interpret their feelings correctly. Are we helping them communicate effectively or not? We must be wary of projecting our own subjective experience on the situation. We must be able to contrast our version of events, our subjective interpretations with those of others, whether other care staff or family members. For how we might like to be treated in this or that circumstance will have sprung from our own experiences, sensibilities and needs. A patient's will be different. The world from where a patient is sitting is always different.

According to the principle of *primum non nocere* (first, do no harm), our primary responsibility in the care centre is to ensure a patient's safety and their health (disability is often accompanied by other pathologies). The right to privacy, although important, takes second place. So, for instance, it is no good rigidly protecting a patient's intimacy if, in doing so, we put them in danger. A patient could slip in the shower or suffer convulsions and we be none the wiser because the shower curtains are pulled across. We must prioritise our protocols with safety in mind. Not having shower curtains should not necessarily infringe standards of decency, if we avert our eyes. It is a look and its intention that makes an action ethical or unethical. Inspectors must be made to understand the context of the needs of residents.

Sexuality and intimacy

The sensual and intimate dimension of a patient is sometimes forgotten about or projected as that of a fully capable individual. The mental age of some adult residents, however, is so young that they have not developed a sense of modesty and do not seek out intimate contact. But this is not always the case. We must be attentive to all of a person's needs and desires and act in their best interests. So, many residents have a sexual dimension and have developed a sense of intimacy. If we are to respect the whole person, we must accept this side of them too. Although there is no need to encourage a person's sexual needs, neither should they be denied where they exist.

Personalisation vs. homogenisation

It is necessary to avoid over-regularising habits because, as people, residents deserve variety as much as possible. Of course, routines offer a sense of stability and order but, as the Ancient Greeks used to say, 'nothing in excess'. Regularising behaviour, without making exceptions, can turn people into machines, and it ceases to matter who is receiving care and who the care giver is. Homogenising the daily routines of residents leads to impersonal care. Where large numbers of residents co-exist, rules and regulations must, of course, apply. But in the same way we differentiate between patients on a medical basis (who needs the allergy treatment? who is the diabetic?) we

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[8] SERRA, M. *Quiet*. Barcelona: Empúries, 2008.

must do the same at the care level. Personalised care comes from varying, however slightly, resident's daily routines. Care centres tend to be large organisations, with a number of professionals and many patients and we must all make allowances for this. But we should never forget who the service is intended for. As a question of priorities, which comes first? Making things easy and efficient for care-staff and the centre? Or ensuring the well-being and quality of care for patients? The latter will result if we personalise care and treat residents as individuals, as far as possible. If we treat everyone identically, keep things neat and tidy with everyone in the same room, at the same time, it begins to seem that the services are designed to benefit those who work there. This would compromise the real object of the service, its legitimacy and professional mission. The fundamental challenge is to strike the balance between logistics and efficiency on the one hand and excellence in personalised treatment and care on the other.

Conclusions

Since we must fully respect both the physical and the moral dimension of the individual in all their variety, we must remember not only to ensure that residents eat and drink, are clean and take their medication, but we must also remember that an essential part of their lives depends on interaction and the relationships developed with carers, care-staff and family. Despite their inability to reason, they have dignity and deserve our full respect and attention. We must dignify their dependence.

The way in which a society treats its incapacitated members tells us much about its levels of solidarity. Recalling Rawls and the 'veil of ignorance', most people, if ignorant of what their socio-biological lot would be, would favour a just society (solidarity) over and above entering the 'lottery of birth'. In a fair and just society those that emerge most well-off from the socio-biological lottery would help minimise the disadvantages facing the least well-off. In a 'lottery of birth' society the law of the jungle, of animals, prevails, where there is no sense of ethics or human dignity. In such a world the severely mentally disabled are doomed to exclusion by simple 'natural selection'.

The degree to which fortune affects the individual is inversely proportional to the fairness of the society in which they live. Being incapacitated is the product of chance, but it would be doubly unjust if, because of this condition, one was doomed to a lifetime of undignified treatment. We must continue to fight to ensure that the severely mentally disabled do not lose what capacity they have for interrelation. We have to support them in fighting for a life that is worth leading, despite their condition. We must fight against 'diagnostitis' and the deterministic view that if a person cannot lead a normal life and has no useful social function, then that life is not worth leading. As long as someone is there to celebrate their dignity, then they will 'find' quality of life. As Frankl says, a man who "knows the 'why' for his existence ... will be able to bear almost any 'how'." A society that treats its incapacitated with dignity is giving them a 'why' to live. Together, we can help them find a 'how'.

Organisational ethics in care services for the severely mentally disabled: ethics committees and codes of ethics

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1. Ethics for organisations?

Yes, ethics for organisations. But aren't ethics meant to be a private affair which depend on the conscience of the individual? Yes, that is so. But does that rule out the possibility of applying ethics to organisations? Do you think organisations have an ethical conscience? A soul, some would say.

Humans, unlike any other creatures, are accountable for their behaviour. We justify ourselves because we are inherently moral beings. Other creatures adapt to the world around them, but do not seek to justify themselves before it. According to Adela Cortina, organisations are a human construct designed to fulfil our 'internal goods'. For this reason, therefore, they must account for themselves in serving this purpose. In this sense, yes, we can talk about an organisation's ethics.

According to the classical definition, ethics is the discipline of the study of values. And, though rarely stated specifically, organisations do have values. Adela Cortina believes that '*an institution is characterised by its explicit consideration of a set of values, with which it tries to make its members identify, perfecting the motives of their actions and educating them in this regard*'.[1] Organisations, businesses and institutions are today more important than ever. Some wield more power than countries. We could even go so far as to say that human action has a *specifically organisational* dimension.[2]

For many of us, our life project develops largely within organisations in which we are more than just individual elements with individual life ambitions. We are instead deeply immersed in an organisational project which is greater than its individual members, without which it would not be viable.

But is this really the case? Do we not go into our respective organisations just to 'do a job'? To do what our boss or top management determines. Our life plan for happiness – does it really play itself out here? If organisations want their members to answer yes, they must treat them as autonomous, discerning people, indeed as 'valid interlocutors' with their own opinions to express. But this is not always the case. Unfortunately, it is not often the case. And when it is not the case, can we still talk about ethics in these organisations? Yes, although they may be authoritarian, hierarchical and coercive and leave little room for dialogue. Some would say that this type of organisation is good for business. I would argue that ethical organisations are profitable too.

Up until now I have argued on principle and conviction. But all ethical debate should consider both deontological and consequentialist theories. Here are a few arguments:

a) Gaining legitimacy. Even more important to organisations in which it has been lost. Helps rebuild trust.
b) As a differentiating feature, to gain competitive advantage. Organisations can stand out on their services and products, but also on their values. The latter will influence that organisation's products and services and enhance overall quality, for quality also has an ethical dimension.
c) Because rules and regulations are seldom enough on their own. And regulating the mass of detail would be impossible. Legal regulations represent minimum standards which as organisations we hope to surpass. We want the best organisation possible. We want organisational excellence.

To summarise, organisational ethics are a basic necessity although some think it is just a fad. Conill distinguishes between fad and necessity in applied ethics. The main feature of a necessity is that an internal good is at stake. Ethics deals with values and the internal goods of organisations. Ethical practice in business serves to shape the 'collective responsibility' to which Camps refers in her work in which she equates organisational ethics to the ethics of collective regulation[3].

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1. CORTINA A. *Ética de la empresa*. Madrid: Trotta; 1994.
2. LOZANO JM. *Ética y empresa*. Madrid: Trotta; 1999.
3. CAMPS, V. *Una vida de calidad*. Barcelona: Ares y Mares: 2001.

2. Civic ethics as the foundation for organisational ethics: moral pluralism and minimum ethical standards

The pure ethical framework within which we must understand organisational ethics is that of civic ethics which accepts moral pluralism provided minimum ethical standards are upheld and which correspond loosely to the stages of development of the theory of human rights. Civic ethics is neutral to an individual's happiness, its purpose is to uphold minimum standards. And as the backbone of society, our institutions should strive to promote and respect ethical standards. Many are eventually set down in law, but not all, for this would be impossible.

Moral pluralism occurs naturally in organisations. This is the way things are. Differences in thinking can lead to ethical conflict; it is harder to reach agreement in these organisations than in those governed by a 'single code' in a society with a single political party, official religion or, even, a single trade union. In pluralistic societies, organisations tend towards diversity. The paradox is that many organisations appear to be the same because their values are indistinguishable or go no further than the desire to provide goods and services and the accruement of wealth.

3. The history of organisational (or business) ethics

A 'reductionist' approach to the obligations of business or organisations (both terms are used indistinctly) is what prompted the birth of business ethics. The theory gained attention in the 1970s as part of a systematic critique of business practice in the light of the social consequences of its actions. Remember, the larger social ethics of the epoch focused on demanding social rights and defending the rights of minorities. The classic article by Milton Friedman in 1970, which argued that the only social responsibility of business was to increase its profits for shareholders, is considered by many scholars to have given rise to this area of applied ethics. In response to this edict, two major conceptual frameworks were developed:

a) There was the theory that supported corporate social responsibility, given that companies are organisations that interact with society and, as such, should be held to account for their actions in that society.[4]

b) Another approach stressed that the ethical responsibility of companies should take into consideration the interests of all of its stakeholders, particularly its employees, clients and suppliers. I alluded to this concept above when I referred to 'valid interlocutors'.

4. The institutionalisation of organisational ethics

Having briefly explored the moral justification and historical context of this branch of applied ethics, how do we go about putting it into practice? What actions should we take and what indicators could we bear in mind when deciding how best to implement and institutionalise an organisation's ethical standards? Lozano tell us that the *Centre for Business Ethics* conducted a survey in 1986 on what factors to take into account when assessing best ethical practice within organisations.[5] The results concluded that the implementation of code of ethics, ethics committees, judicial boards, access to a business ombudsman, ethical education and social impact assessments were among the most important factors.

It is in the field of healthcare that most of our efforts have been concentrated in a desire to explore the ethical dimension of healthcare organisations and how this relates to healthcare quality. The link between ethics and quality is too readily forgotten if companies apply 'ethics' just to conform to 'etiquette'

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[4] Available at http://ec.europa.eu/employment_social/soc-dial/csr/pdf/098-ACA_GESES_Spain_020108_es.pdf (accessed 16 May 2009).

[5] Op. Cit. 2.

rather than to promote true ethical thinking. Simon's collection of papers on healthcare organisational ethics[6] sought to perform a 'comparative analysis on the consideration of ethical issues in the criteria and standards by which the different accreditation systems measure quality in healthcare institutions and organisations' [7] This objective was based on the hypothesis that 'whatever the quality model chosen by a healthcare organisation by which it is to be assessed, managed, certified or accredited, whether already in use or newly created, it should be articulated and used in such a way as to offer explicit guidance on applying ethical standards within an organisation if the latter is to become an institution of excellence'.[8] I quote extensively from this work as contributing author because I feel it allows us to see that concretion is not only necessary, but possible. To conclude, the article highlighted that the subject of this paper, that is ethics committees, was a very useful quality indicator.

At the beginning of this section, we stated that ethics committees are an effective way of institutionalising ethical best practice in organisations. Despite this, with the exception of healthcare organisations, ethics committees appear to be infrequent. They are often associated with seeking punitive action[9] rather than as a means of promoting action for positive outcomes. The reality that ethics committees are a mechanism by which to institutionalise ethics within organisations is recognised by Victòria Camps, who believes that, together with codes of ethics, they are the most commonly used instruments in healthcare organisations. Committees appear to have two primary ways of acting:

a) Through repression and control
b) Through persuasion and debate

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6. SIMON, P (Ed). *Ética de las organizaciones sanitarias. Nuevos modelos de calidad*. Madrid: Triacastela; 2005.

7. Op. Cit. 7.

8. Op. Cit. 7.

9. An example of this can be seen in the course of action taken by an ethics committee for an automobile company. News item available at http://www.lukor.com/not-neg/empresas/0406/28123659.htm (accessed 16 May 2009).

Camps believes that the second option should prevail. Let us return to this point later.

5. Healthcare ethics committees: the institutionalisation of organisational ethics in healthcare institutions

As mentioned above, healthcare ethics committees (HECs) are a useful mechanism to institutionalise ethics within organisations. In other words, they are mechanisms by which to ensure that the ethic of collective responsibility is complied with and monitored. As the main subject of this paper, this section describes at length the origins, types, functions and development of ethics committees in Spain and, closer to home, in Catalonia as well as describing their main problems and future prospects.

5.1. Origin, definition, functions, types and origins of HECs

I will cover this point only briefly as it is, by and large, well documented in the literature.[10] It is worth knowing that the first ethics committees sprang up in the United States at the end of the 1970s and beginning of the 1980s. There are three main types of ethics committees, dealing respectively with clinical research issues, the provision of patient care (the subject of this paper) and issues of national concern. In Spain, they sprang up in this order, the newest being the national ethics committees of which there is one at state level and several at regional level. Similar committees can be found in other Western nations. Of the three types of committee, it is the healthcare ethics committees which are best suited to self-regulation. [11]

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10. The following are excellent examples: ABEL F. Comités de bioética: necesidad, estructura y funcionamiento y COUCEIRO A. Los Comités de Bioética origen, composición y método de trabajo at COUCEIRO A. *Bioética para Clínicos*. Madrid: Triacastela; 1999; WILSON J, GLASER JW, RASINSKI-GREGORY D, MC.IVER J, BAYLEY C. *Healthcare Ethics Committees. The next generation*. Chicago: AHA; 1993.

11. See V. Camps *Una vida de calidad.*

Healthcare ethics committees, and bioethics in general, have developed thanks to a number of ground-breaking cases, the most important of which was the so-called Quinlan case in the early 1970s.[12] A young woman, Karen Quinlan, collapsed into a persistent vegetative state at a time when little was known about the condition. After a series of rulings by the courts following her parent's request for the ventilator to be removed, the State Supreme Court ordered that an ethics committee or similar body be consulted. Other cases which significantly furthered the development of formal ethics committees in healthcare institutions include:

- Clinical Research Committees.
- The Harvard Medical School Committee set up to examine the definition of Brain Death.[13]
- The Baby Doe Case.[14]
- The Ethics Committee at the *Hospital Sant Joan de Déu* in Barcelona, particularly relevant to us because of its proximity.

These early examples were echoed by a number of similar commissions and professional associations including the *President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioural Research* and the American Medical Association's *Guidelines for Ethics Committees in Healthcare Institutions* adopted in 1984. The first appearance of ethics committees in the United States around this time came as a result of the intense bioethical debate generated by changes in healthcare-patient relationships, developments in clinical research and technology, and problems with the distribution of healthcare resources.

Ethics committees began to take hold increasingly in the Unites States with three clearly recognised roles: to advise on individual cases, to establish guidelines for institutions and to promote bioethical educational programmes. Advising on individual cases, as we shall see below, has always been the prime function of a committee. Our own definition of a healthcare ethics committee (HEC) is an "Interdisciplinary advisory committee set up to analyse and advise on ethical conflict in healthcare institutions with a view to contributing to improved healthcare for patients". [15]

5.2. The development of HECs: the situation in Spain and in the West

In 1995[16], the Joint Commission for Accreditation of Healthcare Organization[17] added new criteria under the 'Patient Rights' chapter of its Accreditation Manual. The title was then changed to 'Patients Rights and Organizational Ethics'. This was significant for two reasons:

a) It linked organisational ethics to quality in healthcare institutions.
b) It recognised an obligation, noted in the accreditation manual, for healthcare organisations to have a mechanism in place for the consideration of ethical issues.

This obligation quickly drove institutions in the United States to establish HECs, as Joint Commission accreditation was a condition of licensing to offer public healthcare programmes such as Medicare and Medicaid. The establishment of healthcare ethics committees as a result of this obligation, as we will see below, has not been without its problems. Public concern and interest in American society also played a vitally important role in their development in this country.

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[12] A brief summary of the Quinlan case is available at: http://bioetica.udesarrollo.cl/html/documentos_casos_emblematicos_karen_ann_quinlan.html (accessed 18th May 2009).

[13] *A definition of irreversible coma*. Report of the Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death. *JAMA*. 1968 Aug 5;205(6):337-40.

[14] A brief summary of the Baby Doe case is available at: http://bioetica.udesarrollo.cl/html/documentos/documentos/CasoBabyM.pdf. (accessed 18th May 2009).

[15] Definitions may vary. I have chosen here to use the definition of our own Corporació Sanitària Parc Taulí as it appears in the Centre's internal rules.

[16] *Joint Commission for Accreditation of Healthcare Organizations*. Accreditation Manual for Hospitals 1996. Barcelona: SG Editores-Fundación Avedis Donabedian, 1995.

[17] Originating in Canada and USA, the organisation now provides healthcare accreditation around the world.

All the above explains why the national survey on "Ethics Consultation in United States Hospitals"[18] published in 2007, found that 81% of all general hospitals and 100% of hospitals with 400 beds or more had established Ethics Consultation Services (ECS), which perhaps explains why ECS and HECs are now institutionalised and bureaucratised in the United States. However, it is also the case that these committees have developed in a non-homogeneous manner, few evaluations have been carried out and that there is scant information available on their functionality. My article on the subject written in 1999[19], mentioned a number of shortcomings which, unfortunately, still persist today.[20] [21]

Most autonomous regions in Spain require that their healthcare ethics committees be accredited in law. The first to regulate on the matter was Catalonia in December 1993. Although minor aspects vary between autonomous regions, HECs essentially share the same objectives and interdisciplinary structure. As a result, HECs are now common in many hospitals, healthcare centres and mental health centres.[22]

The development of HECs in other European countries came slightly later. The first in a series of UNESCO guides on bioethics committees, for instance, was published as late as 2005.[23] The UK experience of healthcare ethics committees is also worthy of note.[24]

I have dwelled mostly on the North American experience because this is the birthplace of bioethics and where the most important developments in this field have taken place. And because of the parallels with our immediate area, Catalonia, where an accreditation system for hospitals in line with that developed by the Joint Commission has already been established. There is potential for extending the system to other autonomous regions throughout Spain.[25]

Our accreditation system is based on a number of existing quality accreditation programmes including the European Foundation for Quality Management (EFQM), the Health Quality Service (HQS), the International Standards Organization (ISO) and the Joint Commission for the Accreditation of Healthcare Organizations (JCAHO) among others. The accreditation requirements promote the establishment of committees as a sign of an organisation's commitment to ethics quality management.

However, this 'top-down' approach to the establishment of ethics committees has not been problem free. In many cases they have been established merely to satisfy "external requirements and, as a result, have failed to internalise the conviction that quality ethics are as important as other aspects of healthcare"[26]. This is one of the causes of the 'Failure to Thrive' syndrome which Kuczweski described in 1999 as the norm rather than the exception in US HECs.[27] The syndrome has a series of related problems:

a) The clinical relevance of the committee is increasingly questioned as healthcare professionals are unaware of its existence.
b) Absenteeism of members in committee activities and non-representation of the organisation's most important healthcare departments.
c) Doubt in members' minds on the point or usefulness of the committee.

According to Kuczweski, the failure to thrive of ethics committees was ironic in a country that was at the forefront of bioethical investigation, where most hospitals had their own HECs or similar committees and where professional associations advocated participation in them.

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[18] FOX E. et al. Ethics consultation in United States Hospitals: A National Survey. *American Journal of Bioethics*, 7(2): 13-25, 2007.

[19] HERNANDO P. *Evaluation of healthcare ethics committees: The experience of an HEC in Spain*. HEC Forum 1999; 11(3): 263-276.

[20] Op. Cit 19.

[21] HERNANDO P, DIESTRE G. "La situació actual dels comitès d'ètica asistencial". *Bioètica i debat* 14 (54). Sep-Dec 2008.

[22] In Catalonia, there are 49 such accredited committees. 55% of them have been set up since 2000.

[23] Available at http://www.unesco.org.uy/shs/fileadmin/templates/shs/archivos/guia1.pdf (accessed 18th May 2009).

[24] See http://www.ethics-network.org.uk/ (accessed 18th May 2009).

[25] See http://www.gencat.cat/salut/depsalut/pdf/essencials2005.pdf. (accessed 18th May 2009).

[26] Op. Cit. 23

[27] KUCZWESKI, MG. "*When your Healthcare Ethics Committee "Fails to Thrive"*". *HEC Forum*. 1999; 11(3): 197-207.

Later, the same journal, *HEC Forum*[28], dedicated an entire volume to this topic from a number of viewpoints. It concluded that the failure to thrive of ethics committees was often associated with poor leadership and weak institutional support as well as a tendency to centre exclusively on the advisory role of the committee, a point on which I agreed in the same publication[29]. In my experience, there are signs of this 'syndrome' closer to home, too, although this view is not shared by Ribas who has studied healthcare ethics committees in Catalonia. [30] It is my view that the experience of the United States will be repeated in Spanish HECs, with the attendant pluses and minuses. As Diestre so succinctly puts it "… the problems here are even greater as bioethics in general play a smaller role and the training of professionals in this field is poor."[31]

Although there are other important areas we could look at, such as the implementation of committees[32], how professionals are kept informed and how they are evaluated[33], we will not go into them here as they are tangential to the core of this discussion.

5.3. Lessons learnt from the experience of ethics committees in healthcare institutions (HECs)

a) They should be dedicated primarily to achieving quality, ethics in this case.
b) A strong internal conviction should permeate the organisation which supports the development of ethics committees. Simply establishing them in response to external requirements is shown not to work and may even be counterproductive. The same applies internally within organisations. If HECs are imposed 'from above', the committees are shown to fail in the medium term.
c) An ethics committee's role should not be limited to providing advice on individual cases but should embrace its two other traditional functions of promoting bioethical education and establishing guidelines for institutions. That is to say, it should develop a proactive approach to ethical issues over and above a passive one.
d) Ethics committees need time to develop and flourish, and that this does not happen overnight.
e) Like so many other initiatives, it requires strong internal leadership and support from the management.
f) Ethics committees have developed by and large in the healthcare professions, where there is a long tradition of strong ethical principles, now known as 'professional standards'.[34]
g) Committees concentrate on providing support on ethical issues arising from the provision of patient care (informed consent, withdrawal or refusal of treatment, support in decision-making) rather than the ethical issues arising from managing and distributing organisational resources. As their name suggest, they are healthcare ethics committees, not organisation management committees.
h) It is vital that the organisation's professionals participate in the life of the committee.

6. From healthcare ethics committees to business ethics committees

My expertise is largely within the healthcare sector and so the ideas that follow are necessarily limited. It is relatively easy to find references to HECs in

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[28] *HEC Forum*. 2006;18 (4).

[29] Op. Cit 21.

[30] RIBAS S. "Estudio observacional sobre los comités de ética asistencial en Cataluña CEA-CAT (1). Estructura y funcionamiento". *Med Clin* (Barc).2006;126(2):60-66.

[31] Op.Cit. 23

[32] HERNANDO P. El comité de ética asistencial del Consorci Hospitalari del Parc Taulí de Sabadell: tres años de funcionamiento. En : COUCEIRO A, Ed. *Bioética para clínicos*. Madrid: Triacastela; 1999.

[33] Op. Cit. 23.

[34] For an excellent article on this subject see PARDELL, H. ¿Tiene sentido hablar de profesionalismo, hoy? *Educación Médica* 2003; 6(2):63-80.

the non-specialist literature but there appears to be very little written about business or organisational ethics committees[35] and even Internet searches bring up poor results compared to similar searches on healthcare ethics committees. [36]

Lozano and Siurana argue, in any case, that business or organisational ethics committees have grown out of the experience of healthcare.[37] And if HECs have had a relatively short history then, clearly, business ethics committees are still in their infancy although they do appear to be beginning to take hold.[38] In another paper, Siurana states that "ethics committees are a mechanism taken from bioethics with strong potential for growth and development thanks to their interdisciplinary nature." [39]

For the above authors, there are two possible frameworks within which to interpret their operation:

a) From the central European perspective, where ethics committees are a forum for dialogue and debate.
b) From the North American perspective, where the committee's role is to supervise the implementation of a code of ethics and support and assess the management structure. Here, committees have a more punitive role and must respond to negative actions or results within the organisation.

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35. One example that springs to mind is the biotechnical ethical committee of the French Institute for Agricultural Research (INRA). For more information see http://www.international.inra.fr/es/el_instituto/nuevo_comite_de_etica_conjunto_inra_cirad http://www.inra.fr/l_institut/organisation/l_ethique (accessed 18th May 2009).

36. The Spanish Association for Standards and Certification (AENOR) has, of course, its own ethics committee which this year published guidelines on how to implement a culture of corporate responsibility in business. See http://www.nexos.es/actualidad-rse/noticias-rse/649 (accessed 18th May 2009).

37. Lozano JF, Siurana JC. "Las comisiones éticas como mecanismo de integración de la ética en las organizaciones". *Papeles de Ética, Economía y Dirección* nº 5, 2000.

38. Op. Cit. 46. The authors quote a report from the Centre for Business Ethics in 1992 which reported that 23% of companies in the US had such committees.

39. Siurana JC. "Comités de ética en la empresa sanitaria". *Veritas*, Vol. II, nº 17 (2007) 255-279.

In any case, the implementation of ethics committees outside of healthcare would have to take the following into consideration:

a) Whether or not there is already a culture of 'professionalism' in this sector or a tradition of self-imposed high standards of practice that exceed the legal minimums?
b) Is there a willingness to accept that ethical problems are the core of a HEC's work and that its role should be proactive rather than passive?
c) Institutional support is fundamental, but so is professional involvement. The committee should be independent of top management while ensuring that the code of ethics is upheld.

7. Code of ethics

Whenever I take part in a bioethical educational programme, I ask the room whether they can recall any of the articles of their professional code of conduct. The normal response is that no one remembers, although you get the odd doctor who remembers that he should not charge another doctor for his time which was, indeed, a point included in some codes. Nurses, by and large, cannot recite it either. I then ask whether they know anything about the code of ethics of the institution in which they work. The answer is always the same: they are completely unaware of what it says. Based on my own personal experience, I have come to doubt the impact of professional codes on institutionalising organisational ethics.

Despite this, it is a recognised fact that code of ethics publicly articulate ethical commitment and, as such, are a way of assessing a company's ethical standards[40] serving, too, as the foundation for the process of professional self-regulation. [41]

The multiple functions of a code of ethics include the following:[42]

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40. Op. Cit 1.

41. Op. Cit 4.

42. FRANKL, MS. "Professional Codes. Why, how and what impact". *Journal of Business Ethics* 8/2-3 (109-115). 1990.

a) It is a reminder that professionalism refers to values and not just professional skills and competence and that in this sense is an expression of the collective culture.
b) It allows professional self-regulation to take place.
c) It acts as a guide for professional conduct, clarifies what to avoid and defines shared aspirations.
d) It can be educational and serve as a reference for professionals.
e) It can help identify problematic issues.
f) It can influence the attitudes of members of the organisation.

So, codes of ethics can be divided roughly into three types – aspirational, educational and regulatory. Many codes concentrate exclusively on the first point as 'declarations of intention' found in the 'Vision' section of a company's 'Mission, Vision and Values' statement. This statement often constitutes the only code of ethics of an organisation[43] or serves as its inspiration[44]. Often, ideas you would expect to find in a code of ethics are thrown in under the *corporate social responsibility* section in response to normative pressure. [45]

It would be impossible here to reflect the full range of codes of ethics that have been written, just because of the sheer volume of data, but a useful source of information is the *Illinois Institute of Technology's Centre for the Study of Ethics in the Professions*[46] which has collated an exhaustive selection of codes of ethics from across a wide range of disciplines. The healthcare environment is particularly well represented. In general, codes of ethics are considered ambiguous, lax and lengthy. This, surely, will always be the case, since the law is more concrete than morality.

As with so many other questions, the key to developing a successful code is:

a) Ensuring the process of developing the code itself undertakes to:
    - encourage the participation of the professionals involved
    - give professionals the opportunity to discuss its contents freely
    - move away from coercive approaches and focus on the code's educational and aspirational aims.

b) Ensuring there is a follow-up ethical audit to evaluate the effectiveness of the code.

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[43] See Gas Natural at: http://www.gasnatural.com/servlet/ContentServer?gnpage=1-10-1&centralassetname=1-10-BloqueHTML-1300 (accessed 18th May 2009).

[44] For a further example of a limited code of ethics visit the Capio website at http://www.capiosanidad.es/codigo-etico.jsp (accessed 18th May 2009).

[45] This is the case in "La Caixa" where its code of ethics can be found in the Corporate Social Responsibility section under 'Regulatory Compliance'. See http://portal.lacaixa.e s/infocorporativa/responsabilidadcorporativa/ cumplimientonormativo_es.html (accessed 18th May 2009).

[46] See http://www.iit.edu/departments/csep/codes/health.html (accessed 18th May 2009).

Discussion session and written contributions

Introduction

This section contains the contributions to the discussion which followed the papers, together with written contributions submitted later. We have tried to ensure that the material reproduced here is faithful to the original, although to make it easier to follow we have organised it into the following topics:

- Who are our service users?
- Developing services and changing conceptual models in recent years
- Specific ethical problems in caring for people with severe mental disability
  - Privacy and intimacy
  - Self-determination
  - Personalisation
  - Normalisation
  - Families
  - Other issues: healthcare, disturbing behaviour
- Organisations and professionals
- Strategies for addressing values in our organisations

The sections entitled “Who are the users of our services?” and “Development of services and conceptual models in recent years” have been included to provide readers with little or no knowledge of this area with a brief, general overview of the sector to which the rest of the contributions refer.

In the section on “Specific ethical problems in caring for people with severe learning difficulties”, the emphasis was on conflicts regarding privacy and self-determination. However, we also decided to provide brief coverage of other issues to stimulate new discussions and encourage reflection.

It is impossible not to notice the strong commitment felt by participants to those for whom they are caring and to their work in general. Their contributions are informed by the daily reality of their work, including the challenges faced by care professionals and the problem of limited resources, but always with a view to finding specific ways of improving practice with regard to the rights of service users. As a result, it is difficult to separate the issue of privacy from the professional and organisational framework within which it occurs. Despite this, for reasons of clarity, we have decided to organise the contributions on a thematic basis.

The group attributed great importance to the issue of the organisations and professionals involved in delivering care services. There were frequent references to organisational issues, to the quality of care professionals, and to organisational culture, both from the perspective of frontline care staff and from the management perspective of many of our contributors. Indeed, it is precisely because of this tension between the organisation and the care work, so important in this sector, that there is such a need to identify strategies for addressing values. This is the subject of the final chapter of this publication.

We hope you will find this document useful, and that it will generate new questions which will help us to make real improvements to the way in which we care for the most vulnerable individuals.

Josep Ramos
Seminar Coordinator

Who are the users of our services?

Maite González-Nicolás Cerón, Silvia Lobera and María Ángeles Ortega Reverte. *Grup Catalònia*

Any consideration of ethics within organisations which work with people with severe learning difficulties must start by recognising the reality of the person for whom we are caring:

- We are dealing with individuals who suffer from a *disability* and in the majority of cases do not have *legal capacity*, as a result of which they are under the guardianship of another individual or body.
- This disability is *cognitive*, and this means that the individual has a reduced understanding of his or her environment, interpersonal relations, needs and even of his or her own wishes.

- At times this disability is accompanied by *physical, sensory and/or motor disability*, and this is a major additional complication because it means that, in addition to the individual's difficulty in understanding his or her environment, we must also take into account the fact that the external stimuli he or she receives are deficient.
- Often, the individual is *dependent upon family members*, whose understanding of the situation of the individual with a learning disability (LD) varies widely, who may be better or worse placed to fight on behalf of their child or relative, and for whom adapting to the disability may in itself represent a significant challenge.
- Often, the individual lives in a *residential setting*:
  - where there is a responsibility to provide care 365 days a year, 24 hours a day
  - where the involvement of the family may vary greatly (just as the family's response to the situation itself varies)
  - where the individual is usually *here to stay* (in this sector, it is unusual for individuals to move in and out of care)
  - where the individual is admitted as *a last resort* (in the majority of cases, the individual will have attended a special school, a day centre and perhaps an occupational therapy service)
  - where in the best of cases the individual *must share space with another fifty-nine individuals*[1] with severe learning disability.
- At other times, they are individuals who attend *specialist care centres* during the day and live with their families for the rest of the time.
- The situation of individuals with learning difficulties is one which changes, even in the most serious of cases. Health, ageing and deterioration may all require a need to change the type and level of support during the individual's lifetime.

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[1] The regulations state that establishments of this sort must have a maximum capacity of 60 individuals.

Jordi Mir. *Julio Payas Residence and Day Centre for People with Serious Learning Difficulties (Santpedor)*

The typical characteristics of individuals with serious learning difficulties can be summarised as follows:

- mental age/development below 2.5 years of age
- significant percentage of individuals with serious mobility problems (wheelchair users)
- significant percentage of individuals lack spoken language
- significant percentage of individuals unable to control sphincters
- presence of behavioural disorders (aggressive behaviour, destruction of property, isolation, stereotypical behaviour, ingestion of inedible products, etc.)
- high rate of diseases such as epilepsy, respiratory problems, psychiatric problems, problems ingesting food, etc.

Eugènia Llovera and Anna Santaulària. *Atendis Private Foundation*

People with severe learning disabilities have generalised developmental disorders which, together with communication problems (serious problems in the acquisition and use of language), translate into a qualitative and quantitative deterioration of social interaction.

All service users, with their widely varying needs, require care professionals to act as interpreters who seek to enrich and improve the individual's communication, emotional interactions and ability to relate to the environment.

Care professionals and family members alike share a responsibility to help develop the individual's capacity and to configure support which increases the level of understanding and expression of the person being cared for, and to promote the development of skills which enable the interpretation of non-verbal behaviour.

We must start by accepting these personal and social limitations to understand the need to interpret the individual's sounds, gestures, moods etc., contextualise them and use this to aid communication.

Often, however, it is necessary not just to interpret the user's demands or needs but also his or her wishes, moods and interests, on the basis of the knowledge and information we have available. As a result, we must take decisions on behalf of severely disabled service users which condition (for better or worse) their quality of life.

Development of services and conceptual models in recent years

Montse Vilella. ***Villablanca Private Foundation***

In recent years, care for individuals with severe learning disabilities has changed greatly as a result of wider changes in society as a whole. Fifty years ago, such individuals were often shut up at home with nobody outside of the family circle even aware of their existence. Others were cared for on a "charitable" basis, locked up in mental institutions. This second group were directly affected by the transformation in mental health services, which led to improvements in their living conditions, although there are still a few who have been left behind and whose situation is subject to the latest reforms for the "chronically disabled" within the Mental Health Plan.

During the 1970s and 1980s, in the context of the inactivity of the authorities, associations of parents of disabled people played the leading role in creating services designed to include these individuals in society and get them out of the home. These associations are still responsible for managing many services. The pressure exercised by these groups, together with changes in the wider society, led the authorities to allocate funds for these purposes in health, education and social services.

In the early 1990s, a network of centres specifically serving individuals with severe learning difficulties was created across the whole of Catalonia, and many of these centres are represented by care professionals participating in today's seminar. The creation of this network was an important step for disabled individuals and their families, creating as it did a place for them within wider society.

Despite all of this, from the perspective of the rest of society, this group is still difficult to understand, consisting as it does of adults with capacities similar to those of a child of less than five years of age (severe learning disability) or less than three years of age (profound learning disability) and many of less than one year of age. What do we expect of a one-year-old child? How do we look after them? What do we do for them? What dangers does life hold for them? And what if the learning-disabled individual is nearly 6 feet tall? And has very restricted motor abilities because he or she suffered from infantile cerebral palsy? And what if he or she has other psychiatric problems? And neurological problems? And, to all of this we must add that these individuals are not children but adults.

Jordi Mir. ***Julio Payas Residence and Day Centre for People with Serious Learning Difficulties (Santpedor)***

For years, care services for those with learning disabilities was driven primarily by two practical or ideological principles. The first of these is the principle of social integration, which requires that we strive both to ensure the social integration of the disabled individual and to raise awareness in society and promote society's adaptation to individuals with learning disabilities. In other words, we apply a model of intervention which is open and inclusive. The second principle is that of normalisation, which could briefly be summarised as ensuring that individuals with learning disabilities have access to patterns and conditions of daily life which are as similar as possible to those of people without disabilities.

The application of these principles to the work of bodies and services caring for individuals with learning disabilities led to a series of changes, some of which are listed below:

- A preference for using community services (doctors, restaurants, leisure and sports facilities, etc.).
- The organisation of the disabled person's time, distinguishing between work/daily activity and residential or home life.
- Respect for the individual's weekly and annual rhythms.
- The creation of services integrated within the community.

- Respect for the life cycle of individuals with disabilities (childhood, adolescence, adulthood and old age).
- The organisation of campaigns to raise social awareness of people with disabilities.
- Integration in the mainstream school system.
- Recognition of their capacity for work.

Today, the emerging current in caring for people with learning disabilities is the quality of life paradigm. Of the various ways of approaching quality of life, the model which is most widely accepted in Spain is the one proposed by Schalock, which defines quality of life on the basis of eight dimensions:

- emotional well-being
- interpersonal relations
- material well-being
- personal development
- physical well-being
- self-determination
- social inclusion
- rights.

Specific ethical problems in caring for people with severe learning difficulties

Privacy and intimacy

Jordi Mir. *Julio Payas Residence and Day Centre for People with Serious Learning Difficulties (Santpedor)*

The job of caring for and supporting individuals with severe learning difficulties generates ethical concerns regarding the question of privacy. Although we talk about privacy in bedrooms, bathrooms and other spaces, for reasons of safety, supervision, limited human resources etc., the right to privacy may be threatened.

Maite González-Nicolás Cerón, Silvia Lobera and María Ángeles Ortega Reverte. *Grup Catalònia*

One of the classic debates in our organisations undoubtedly relates to the question of *privacy,* given the conflict between the need to protect an individual's privacy and the need to ensure his or her safety. And this is due to the individual's learning disability. As a result, it is a fundamental principle that *privacy should never threaten safety,* either for the individual being cared for or for the care provider.

Pilar Bermúdez. *Vallparadís Foundation*

Some good practice manuals define privacy as the right to be alone, the right not to be disturbed, in those situations where this is what the service user wishes. In practice, this formulation is problematic:

- Some service users express the desire to be alone almost continually. For example, some people with autism prefer isolation to contact with others. Should their wishes prevail even if this means missing out on potentially positive opportunities for interaction?
- Other service users do not explicitly state this desire, and it is difficult to infer from their behaviour their need to be alone. In these cases, should we apply a policy of minimums based on a projection of the social context?

This perspective would appear to provide the basis for current guidelines regarding the use of bathrooms, with the result that there must be an individual closed space for users of centres. In this situation, some of these users display behaviours such as playing with their excrement, coprophagia, self-harm, etc. (not to mention the possibility of epileptic fits), and this may mean that the carer has to provide constant supervision.

If we also take into account the fact that many of these individuals take longer both to urinate and to defecate, we could easily conclude that the application of these guidelines would limit the role of the carer to the job of controlling use of the bathroom, preventing the carer from performing other activities.

In the current context, arguing for spaces which can be used simultaneously by different users is seen as regressive and as undermining users' basic rights, when such a move would actually allow greater supervision (and therefore greater safety) and respect for the rhythms of service users.

Some of the measures mentioned above seem, in any case, to respond to aesthetic rather than exclusively ethical criteria. Why is it acceptable to see children aged three or over in similar situations, but not certain adults?

Montse Vilella. *Villablanca Private Foundation*

It is clear that service users deserve the utmost respect as individuals, and that privacy is a basic right. There are several considerations we must bear in mind:

- Some people will always be dependent for activities of daily living, including their personal hygiene. This means that the active involvement of a third person is almost always required at the most intimate moments. This person must obviously have sufficient training and sensitivity to perform their job without invading the privacy of the person for whom they are caring. And they must ensure that nobody from outside of the service user's close circle is present.
- People with learning difficulties often live in quite large groups in residential homes. As in any home, there must be different areas for different functions, with different levels of privacy. Naturally enough, if someone knocks on the door, they are shown into the living room, not the bathroom. But we also need 'intermediate' spaces for close friends and family.

Everyone working at the centre should be aware of the level of privacy for each space, and who has access to it at which times. For example, the most public spaces are visiting rooms, the gardens, the lounge, etc. In our centre, the dining room, the TV room and activity rooms are semi-public, while downstairs residential areas, including toilets, and the bedrooms and bathrooms on the upper floor are defined as private areas. This obviously determines how staff act. It may require restricting access by visitors to private spaces or preventing a resident with a compulsion for undressing from being naked in a public area.

Safety is very important, and the nature of severe learning disability means that we generally require large, open spaces where it is possible to supervise and help if necessary. To an outsider, this may mean that bathrooms lack privacy. We believe there is a need to reconsider such issues and seek to strike a balance between safety and privacy. In a residential setting, it is necessary to care for groups of people, not just individuals. The nature of their disability means that we cannot allow them out of sight even for a moment, even when they are in the bathroom.

The realities of group living mean that many issues become part of a "collective intimacy". What does this mean? Imagine that I am buying bread in my local bakery and next to me is another customer, whom I have known by sight for years but who I have never spoken to. It then happens that I coincide with this person at the gym. After the class we shower in the women's changing room. The first few times you go to a gym you may be struck by the smell of other people's sweat, but you soon learn that group behaviour involves sharing this space in a natural manner. As a result, within a couple of weeks you can go from not speaking to someone to showering next to them.

We must also remember that people with severe mental disability obviously suffer from major developmental impairments. While they are clearly adults, if we consider their cognitive and emotional development we can see that all of them have a developmental age of less than five years and the majority less than one year. Physical modesty generally develops at around seven or eight years. This doesn't mean that anything goes, but it does mean that the resident's safety may be more important than their privacy, something which is very important for other adults but less important for them. Why don't we find it disturbing to see three mini-toilets in a row in a nursery bathroom? Surely it is not just the size of the toilet bowl?

Perhaps we sometimes fail to realise, when visiting a centre, that we are the ones who pose a threat to the residents' privacy. Is it a public centre or is it the residents' home? And where is privacy located in such settings?

Beatriz Sánchez Rodrigo and Domi Rodríguez Brazal. *El Maresme Foundation*

How do we reconcile the right to privacy with these situations? I believe that the answer lies in remembering the difference between absolute privacy and respecting the right to privacy in so far as is possible, and accepting that when making choices regarding this privacy, the safety of the individual is paramount.

Striking this balance is always difficult. It involves promoting choice and offering options, in a context where identifying activities which are suitable for the severely disabled is far from easy. At the same time, we must remember that the centre is not just an activity centre but is also the individual's home and that it therefore needs to provide spaces for resting and for quietness. This involves observing, listening, interpreting, remembering that life involves social interaction, etc. In other words, it means accompanying without invading, wherever this is possible.

And finally we need to try to share all of this with those family members who are closely involved with caring for their relative, for others who are less closely involved, and for those who find themselves living with an adult trapped in infancy. To share, as far as possible, our work in centres where we care for those with severe disabilities.

We must always act on the basis of respect for the person with a learning disability as we face up to the challenges of new requirements, new illnesses, and new ways of caring for people with disabilities. With respect and professionalism, we can find a way forward.

Eugènia Llovera and Anna Santaulària. *Atendis Private Foundation*

Should we prioritise safety over privacy? Liberty over safety? Standardisation over individualisation? The group over the individual? There are no absolute solutions to ethical dilemmas, and instead these vary according to the individual requirements of each service user. When caring for users with severe disability, whose capacity for autonomy and self-determination is clearly limited, we must focus on the quality criteria for the individual's biological, emotional and social life, which constitute the objective indicators for intervention.

Montserrat Codinachs i Vila. *Sant Tomàs-Parmo Association*

The right to privacy has already been described in some detail by my colleagues. We already have legislation and an inspection regime, but in the day-to-day task of delivering our services we know when we need to prioritise privacy and when safety takes precedent. It is not unreasonable to expect those drafting regulations and carrying out inspections to seek to understand the challenges we face in our centres and the real needs and priorities of people with learning disabilities.

Self-determination

Beatriz Sánchez Rodrigo and Domi Rodríguez Brazal.
El Maresme Foundation

Care services for people with disabilities have developed rapidly over recent years, and have shifted from being charities to operating on a professional basis. This involves a closer focus on the needs, preferences and potential of the service users. Sharing experiences with professional colleagues reminds us that we are not alone and that we share the same challenges when trying to deliver our services in an ethical way.

The fundamental criterion which governs bioethics is that of respect for the human being, for his or her inalienable rights, and for his or her *dignity*. Dignity is closely related to self-determination and the ability to take decisions regarding key aspects of one's own life. This leaves us with the dilemma of how to promote the self-determination of people with severe learning disabilities who often also suffer from physical disabilities. How can we listen to the preferences of people with such major difficulties of comprehension and expression, communication and language? How can we look out for their interests when they themselves are incapable of expressing their wishes, and their condition is often so severe that their families are incapable of looking after them or deal with the situation through a combination of denial and the infantilisation of their children as a way of coping with the fact that their adult offspring have a mental age of just a few months?

Clearly, the professionals who care for people with severe mental disabilities must address a range of issues which have only been identified relatively recently, and we must then extend this discussion to family members and to the wider society.

We must start by recognising that self-determination is important for everyone – including for disabled people, who must be able to make choices within their range of capacities – and by making an effort to ensure that this self-determination is implemented whenever possible. And this means having time and space to observe and get to know the people we are caring for, and tools for interpreting what they tell us, either verbally or with regard to their body language and emotional state. Often, what they are able to express is very limited, and if they are to make choices we need not only to offer then a range of options but also to interpret the results, through a gesture, a blink, or a vocalisation.

Fortunately, the centres where we work with people with severe mental disability have more and more systems to support or facilitate communication, including touch screens and a whole range of other tools and new technologies to promote interaction with people with disabilities. All of this makes life easier, but without the human factor it is pointless, without professionals who believe in the validity of such communication, who value and interpret these tools and attempts at communication, it is no use at all.

It means, then, that we really have to believe in this process. We must be aware that promoting the ability to choose between different options is the difference between an individual participating in his or her own development and that individual having everything imposed upon them from above. We are talking about people who are completely dependent for the basic activities of daily living, people who have difficulty in being understood and who often struggle to control their own impulses, we are talking about people who, in many cases, cannot be alone for a single minute of their lives.

Montserrat Codinachs i Vila. ***Sant Tomàs-Parmo Association***

One of the dimensions of Schalock's concept of quality of life is precisely the question of self-determination. It is difficult but not, I believe, impossible to offer the people we are caring for opportunities to choose, and, furthermore, such an approach is absolutely ethical. And this is despite the difficulties we face, whether due to the characteristics of the individuals we are caring for, their families, the difficulty of the task being performed, the laws and regulations which apply to our activity, or the lack of time and resources. In the seminar, it was also noted that we often struggle to identify the likes and dislikes of our service users. This is true, but it is also true that it is our duty to try to identify these preferences, so that service users can be happier and feel that they are being cared for adequately. In the centre where I work, we have managed to discover the likes and preferences of service users by creating spaces where they can choose: choose what they want to eat (sweet or savoury); what activity they like best (music therapy, art therapy, psychomotricity); whether they prefer to stay in the centre or do activities in the community, and so on. Simply by offering these options and observing the facial expression, movements or sounds of service users, we may be able to know whether they want to go on holiday or whether it upsets them, if they like parties and celebrations or prefer calm, etc. In summary, the aim is to give people options; enabling service users to take their own decisions should be a challenge for everyone working in this sector.

Of course, we cannot deny the difficulty of offering the possibility to choose, but this should not be an excuse for doing nothing. Sometimes we have to struggle to make any progress, but we must remember that service users are entitled to the right to choose.

Often, the concept of self-determination for people with severe mental disability is treated as somewhat abstract, but we need to be capable of giving it expression in the day-to-day activities of our centres and in ways which match the capacities of our residents. I know that at a theoretical level the concept goes far beyond simply choosing a snack, an activity, or whether to go to a party, but it would be wrong if theory were to lead us to neglect daily practice and to lose sight of the people for whom we are caring, and their characteristics, interests and priorities.

Another concept we often encounter in our services is that of paternalism and over-protectiveness, particular in the case of direct care professionals and students. I am aware that the concept of paternalism is a very broad one, and does not only involve over-protection and the loss of autonomy by the individual with mental disability, but what is at stake here are the rights of our service users, and it is our duty to defend them.

Pilar Bermúdez. *Vallparadís Foundation*

For residents, exercising the right to choose involves both selecting the activities he or she wishes to engage in during the day and decisions about how to use his or her free time.

We should remember that, not so long ago, the one thing that many of the people cared for in our centres had was vast amounts of free time. Those moments, which for many represent an opportunity to engage in activities which are both enjoyable and enriching, for others entail the consolidation of habits and behaviours which not only reduce the person's opportunities for growth, but may even be harmful for the individual involved. Stereotypical or obsessive behaviour, among others, often fill the time of these individuals if they are not provided with alternatives (which, obviously, should be designed to be enjoyable) but which at the same time restrict free choice.

At such times and under the guise of the right to choose one's activities, some patients spend the greater part of the day lying in bed, without taking part in any of the options available. And attempting to ensure that they take part in these activities may, at times, lead to conflict. Does exercising this right, then, not carry with it a greater danger for the person, in so far as it may significantly reduce their opportunities for development and interaction (with the environment, with others)? If access to other settings is gradually restricted, does this not contradict the principle of normalisation?

The broad, generalised need for support of the people we are caring for means that it is impossible for them to act, express themselves and think without the support of another person.

Food may be the setting in which we most often have the opportunity of identifying the likes and dislikes of our service users. If their preferences come into conflict with serious health problems, it seems obvious that health considerations should take priority (despite the fact that in those with mild learning disabilities the consumption of alcohol and tobacco is considered acceptable). However, what decision should we take with respect to the issue of whether a person should be put on a low calorie diet when the individual concerned has expressed a clear dislike for the kinds of food which this diet entails?

My aim here is not to introduce restrictions in a setting in which the application of rights and the consideration of ethical issues has often been subordinated to other considerations (financial, organisational, efficiency, etc.). Instead, my desire is to propose a space for reflection in which we can reformulate, from a realistic perspective, what it would mean for our interventions to be person-centred and based on the respect for the rights of the individual.

Maite González-Nicolás Cerón, Silvia Lobera and María Ángeles Ortega Reverte. *Grup Catalònia*

Self-determination should always be understood in terms of individuals' needs to take decisions about themselves, about their plan of action. Often it is the family which takes the decisions, while the person with a severe mental disability is ignored. Actions in this sphere would consist of various specific stages:

- Learning to interpret the signs of well-being offered by the person we are caring for. Seeking forms of communication, even if these are very basic, and incorporating them into the individual plans of service users. As a result, it is essential to pay attention to *communication* in terms of both expression and comprehension, and to verbal and alternative or supplementary channels.
- *Extend the range of activities included in the activity programmes of residences.* Avoid tired, repetitive and uncreative programmes. It is only by increasing the number of options available for individuals to participate in that we can offer them a real opportunity to choose or "decide" (in line with their abilities).

Personalisation

Montserrat Codinachs i Vila. ***Sant Tomàs-Parmo Association***

Those of us who work in these centres and who share the mission of caring for the people who live there often face situations which force us to question our daily care practice, which make us think and which require a response.

It is certainly true that in residential settings such as ours, where we are caring for people with severe mental disabilities who often have additional mental or physical health problems, there is a tendency towards depersonalisation. The operational and organisational demands of our centres mean we often end up prioritising organisational efficiency over individualised care, creating protocols and guidelines, records, timetables, working groups to systematise and standardise operations in order to improve the quality of life of the people we are caring for, etc. In settings such as ours –where people live in a group, where plans are built around staff working hours and shifts, where there are fixed ratios of service users to staff– it is sometimes difficult to balance organisational and personal demands.

Jordi Mir. ***Julio Payas Residence and Day Centre for People with Severe Mental Disabilities (Santpedor)***

The standardisation of the activities and the rhythms of life to which people with disabilities are often subjected in large part reflects the potential or actual needs of organisations. I am referring to things as straightforward as mealtimes, the variety of menus and the possibility of choosing one's food, the time at which one goes to bed or gets up, participation in activity programmes, etc. It is not easy to solve these problems and ensure that people are able to exercise their rights, because doing so must be done within the context of budgetary restraints, employment agreements, staff entitlements, organisational options and the rights of other service users.

For example, making bedtimes more flexible might increase the workload to a level where existing night shift staff could no longer cope, and require an increase in the numbers of night staff which would be beyond the service's existing budget.

Normalisation

Jordi Mir. ***Julio Payas Residence and Day Centre for People with Severe Mental Disabilities (Santpedor)***

The current paradigm of caring for people with mental disability is based on a model of quality of life, and within this context there is increasing debate around how we should understand the concepts of "social integration" and "normalisation". At issue is whether "normalisation" should be understood solely in terms of accessing normal patterns of life (where normality is understand as the usual conduct of the majority of people) or whether we should understand "normalisation" as the recognition of the specific requirements and disabilities of the individual, and the recognition that these should be treated *normally* in a specific, individual manner. Examples of this debate include:

- Should children with severe, broad spectrum mental disabilities be cared for within a school framework (mainstream schooling or special education) or do they need specific care centres which are not based on the school model (activities, professional profiles, timetables, calendar, etc.)?
- Should people with severe mental disabilities be cared for within the normal healthcare network, with the same criteria which are applied to the rest of the population or do they need special treatment which reflects their unique requirements? We need to bear in mind that they may find it difficult to wait, that they may suffer from behavioural disorders, offer little or no cooperation during medical examination, etc. and that these patients often suffer from specific health problems such as epilepsy, motor disorders, digestive or respiratory problems, etc.

In the first example, on the one hand it is easy to understand parents who demand centres which cater for the specific characteristics of their child and this might seem like the right option, but we should also remember, for example, that integration and inclusion help raise awareness of people with disabilities among the rest of society, starting with the other students at the school, with the result that inclusion and integration serve as a means of educating people in values and attitudes towards people with disabilities, and have promoted greater respect, recognition and understanding of their needs.

Montserrat Codinachs i Vila. *Sant Tomàs-Parmo Association*

Normality is a concept which has arisen several times during this discussion. As has already been noted, we cannot deny the reality, in our services, that the care we offer could be better suited to the needs of the people we care for and, as a result, improve their quality of life. During my career I have experienced situations where as professionals we have given relatives expectations which do not accurately reflect the reality of the individual, usually in the name of the concept of *normalisation*. Professionals working in residential services such as ours have to attend to the family, who often lack adequate information about their child's care needs. We must avoid simply falling back on concepts, theoretical models or academic literature when talking to families. It is the families and the person with the disability who live the reality of their situation and who usually have the best understanding of the portfolio of existing and future services. We need to listen to them and accompany them, taking care not to ignore their explanations and their experiences, and making sure that what we offer them reflects the needs of the person with a mental disability.

Pilar Bermúdez. *Vallparadís Foundation*

We need to try to promote decision-making, with regard to everyday issues and in so far as the individual's capacities make this possible. Sometimes, however, personal choices may come into conflict with the principle of normalisation (according to which activities, objects, etc. should reflect a person's chronological age). If a person with a mental disability has a clear preference for objects and behaviours which are considered childish (soft toys, songs, cartoons, etc.), should these be replaced with supposedly adult alternatives?

There is no question that there is a tendency to infantilise people with severe learning disabilities, but once we are aware of this risk how should we respond to preferences which, while they can be classified as childish, continue to be important in adulthood? And is attempting to modify these preferences not simply an attempt to project what we want to see, to impose a façade of normality?

Montse Vilella. *Villablanca Private Foundation*

Some time ago, care professionals and families rejected the option of hiding people with disabilities and chose the path of normalisation. This normalisation was understood as the inclusion of people with mental disabilities, accepting them as they are. Francesc Tosquelles, a French psychiatrist who has advised the Grupo Pere Mata for many years, had already said in the 1960s that "including means accepting difference". The journey has not been an easy one, but it has been rewarding for those of us lucky enough to participate in it. A few years ago, if you left the centre with a group of residents there would be a spectacular reaction from passers-by. Some respectful, others less so, and all noticeable. From this we moved to 'charitable' comments along the lines of "What a wonderful job you're doing", and now we are working towards a situation where people simply say "Good morning!"

These changes have obviously been linked to the rise of the welfare state but, as often happens, we find ourselves facing the paradox that the people that the welfare state reaches last are precisely those who need it most. The government improves services for this group just when the welfare state as a whole is facing a crisis.

Those of us who work with adults with mental disabilities understand that this group of people should enjoy their place in society as a matter of social *justice*. By right. We often use the term "citizens with full rights" when talking to general audiences, representatives of the authorities, families and among professionals, and I believe that this is where ethics comes into play: social ethics and ethics in performing the work that society has entrusted us with. "A society which is concerned with values should consider how it cares for its most vulnerable members," is another of the phrases we often repeat.

We have said that normalisation means accepting difference. Knowing what is normal means having a detailed understanding of the individual's abilities and of his or her limitations. We have to create a situation where what is normal for them is normal for society. Years ago, wheelchairs were confined to domestic settings, but now they have been normalised. What else should we normalise? This is a very important issue, and we must strive not to fall into the trap of projecting our needs and wishes onto others. While there is no doubting the truth of the maxim, "wish for others that which you would wish for yourself", we should complete this by saying, "take notice of what others are like, and try to ensure they have everything they need."

Families

Montserrat Codinachs i Vila. *Sant Tomàs-Parmo Association*

The attitude of the family sometimes raises doubts as to our practice and our ethics with regard to the person we are caring for. Families can interfere with our work and what we are trying to do, refusing to allow their child or charge to participate in the activities offered by the centre and which we believe constitute the best care and treatment. What should we do in such situations?

Eugènia Llovera and Anna Santaulària. *Atendis Private Foundation*

The family shares responsibility for how the person with a severe mental disability is looked after, and as such should play an active part in the organisation and share its values and expectations. In other words, we need a system of shared values between all parties, which gives meaning to everything we do.

Jordi Mir. *Julio Payas Residence and Day Centre for People with Serious Learning Difficulties (Santpedor)*

The individual with a severe mental disability is generally in a position of total and permanent legal incapacity. He or she will, for example, have been unable to choose whether or not to enter a residential or daycare centre, and is usually unable to express a complaint or a suggestion. This incapacity raises ethical concerns with regard to the participation of families as representatives of the interests of the person with a disability.

This triangle involving the person with a disability, the family, and the care service sometimes generates "delicate" situations other than those already mentioned. How should we act when we believe that the interests of the family do not coincide with those of the person with a disability? And what should we do when the family is clearly opposed to certain treatments that we believe to be necessary? (For example, in the case of aggressive behaviour which could endanger other service users?)

Many professionals advocate improving the participation of relatives and developing more person-centred models, but we should also remember that many organisations have experienced situations where relatives have wielded real decision-making power and this has led to situations which are scarcely viable. It is difficult to be both judge and jury and to maintain a fluid dialogue between general and personal interests. And we also need to question paternalistic attitudes which may exist in organisations, and consider how to strengthen the role of the relative.

Other issues: healthcare, disturbing behaviour

Montserrat Codinachs i Vila. *Sant Tomàs-Parmo Association*

I would like to set out some thoughts about the public healthcare received by the people we care for. After much effort, cooperation and agreements, our services now enjoy adequate healthcare, but for many years we suffered from the ignorance and lack of training of health professionals with regard to severe mental disability, with respect both to mental and physical health issues. I believe that specific training about mental disability should be included in medical curricula, given the fact that the care received by people with mental disabilities is not the same as that received by the rest of us, and I speak from experience. It is also our duty, as professionals, to demand and guarantee quality healthcare for our service users.

Jordi Mir. ***Julio Payas Residence and Day Centre for People with Serious Learning Difficulties (Santpedor)***

There are other problems in our care settings, such as physical restraint and excessive medication. The first of these includes physical restraint to prevent self-harm or harm to others, or physical restrictions such as locking doors at night to prevent people escaping, consuming toxic substances or other dangers. We also need to take great care to avoid excessive use of medication generally prescribed to treat behavioural disorders.

Behaviours such as disrespect, shouting or physical punishment are clearly unacceptable, but we also need to consider the ethics, for example, of attending to someone who is doing the toilet but not speaking to them or giving them a smile, of how we wake people up, or of whether we give a quadriplegic person enough time to swallow.

We are considering ethical issues which should be expressed in attitudes. Some specialists argue that attitudes are inseparable from techniques and skills, that knowing how to shower a dependent person involves both ensuring that they are cleaned properly and doing this with warmth and humanity.

Within the quality of life framework, another ethical doubt arises and this, in our opinion, is one of the most difficult to address because it involves major social and ideological issues. And this is the question of how to promote settings and spaces which foster quality of life if care facilities for people with severe mental disabilities are home to people who display aggressive behaviour or are emotionally disturbed (shouts, noise, pushing, interrupted sleep, crying, etc.)?

How would we feel if we had to live with someone who was constantly throwing things around, who tried to scratch us, or who wouldn't stop shouting whenever we were watching the TV? We would undoubtedly find it unpleasant. Recognising this fact leads us to accept that there may be some people with severe mental disability whose behaviour detracts from the quality of life of others. In this case, two ethical issues are in collision: the right of some to emotional and physical well-being against the right of others not to be segregated or labelled (aggressive, noisy, with socially unacceptable behaviour, etc.)

Organisations and professionals

Montserrat Codinachs i Vila. ***Sant Tomàs-Parmo Association***

In our sector, staff are often unaware of the values and mission of the organisation in which they work. As a result, they often lack a sense of belonging, one of the dimensions of Maslow's pyramid of needs for professional motivation. It is not enough to talk of an employment contract between the individual and the company, service or organisation. We also have to recognise the importance of the 'psychological contract', the worker's commitment to the organisation which goes far beyond a simple economic exchange. This is an issue which our organisations need to address.

With regard to our organisations' human resources, there is no doubt we face serious challenges such as a lack of regulation of training, high turnover and low salaries. Despite this, we must be capable of transmitting values, a mission, a working ethic, and personal and professional attitudes, as a way of creating this sense of belonging, trust, commitment and teamwork.

If our efforts are to improve the care and quality of life of the person we are looking after, we must work as part of a team of professionals: managers, specialists and care staff. Working together and the transmission of values, working guidelines, attitudes and commitment must involve all professionals. Lack of time or organisational difficulties in residencies cannot excuse working on an isolated basis and failing to transmit positive attitudes. As managers of these services, we must find spaces for the transmission of values and teamwork in order to provide high-quality, professional care.

Meritxell Draper Font, Jordi Gràcia Peiró and Toñi Segura Baeza.
ALLEM Federation

One of the contributions made by the experts at this workshop is a point we had not explicitly taken into account: organisational and management issues.

In our opinion, considering these issues enables us to ensure that our intervention is more effective and inclusive, and at the same time allows us to develop and apply issues we have addressed in training. It enables us to apply our values and, to quote our president Josep Ramos, "to create ethically coherent organisations".

We repeatedly hide behind the excuse of a lack of time, and the dynamics of timetables imposed by the organisations we work for. This makes it difficult to find space for reflection. But we have a curious notion of time in our services, while people with disabilities are in no hurry at all, have plenty of time, and the majority of them stay with us for open-ended periods of time. We would also have more time if we learnt to think about it differently. We are the ones who establish a timetable and identify actions to be performed within a set timeframe, but what about quality of care? We are convinced that the time we "waste" incorporating ethical issues into our organisations is time well invested over the medium term. Hiding behind the excuse of a lack of time is an expression of our fear of change and of a lack of conviction and confidence as to what path we should take and where we should go. It is easy to be distracted from our itinerary, and this itinerary, if it is to be effective, must be agreed upon.

We have considered whether the professionals who make up an organisation understand its mission and values. Do we all share and understand the same idea when we define the values of our organisation, which should form the basis of our interventions?

Maite González-Nicolás Cerón, Silvia Lobera and María Ángeles Ortega Reverte. *Grup Catalònia*

It is essential that we update our training programmes to create space for us to address the issues raised here. These programmes should include the following:

- Induction training for new members of staff, to share the values, goals, mission and vision of the organisation.
- Training in specific intervention methods, so that staff have the resources they need for interventions as part of their daily work, in terms both of specific strategies and the content of activities.

- Training to promote the development of personal resources by staff working directly with people with mental disability.

Eugènia Llovera and Anna Santaulària. *Atendis Private Foundation*

Organisations should have explicit values and be capable of communicating them to professionals through training programmes and active participation. We need professionalisation, stability and continuity (reducing absenteeism, staff turnover, etc.) so that staff play a more prominent role in the organisation.

Jordi Mir. *Julio Payas Residence and Day Centre for People with Serious Learning Difficulties (Santpedor)*

In recent years, organisations which care for people with disabilities have made major efforts to define their mission, their vision and their values. They have created working groups to discuss and define the values which characterise them, and which need to be applied throughout the organisation in order to achieve quality. We have not conducted an extensive enough study, but it is my impression that if we identified the five or six values set out by organisations in their annual reports, websites and other documents and analysed their meaning and content, we would find that a large part of that content is similar or identical across the different organisations which care for people with disabilities.

If this is the case, and the majority of care services for people with mental disabilities form part of the public network of care services, is it logical or ethical that each organisation should have its own values, or should we seek to ensure that people cared for by the public network, whether in Mataró or in Olot, are treated with the same "respect", "commitment" or professionalism"? In this case, we would be talking about the values of the Catalan Social Services System.

Our knowledge of ethics is limited, and is restricted to what we have learnt at the occasional conference about ethics as applied to the social services. Despite this, we have been somewhat surprised to see that the expansion of ethics (the ethics of outcomes, ethics of customers, people, society, etc.)

has contributed to a "universal ethics" whose impact on organisations is very similar to that of quality or excellence models such as, for example, that of the European Foundation for Quality Management (EFQM). We remain unsure as to whether this is a positive or negative development, whether it helps create opportunities for ethical reflection or whether, on the contrary, it may confuse many professionals when we talk about their daily work.

Arantxa Uranga. *Assisted Institute Paulo Freire of Reus*

This is why we urgently need management to demonstrate its commitment to this entire process, given that:

- responsibility must be taken at the highest level for implementing the values which constitute codes of ethics, reflecting the maxim that states, "the more power, the more important ethics"
- management must also use its status as an interlocutor with the administration to demand that those with mental disabilities are treated fairly.

I sincerely believe that if we truly wish to ensure that our values have meaning, then we are *all* obliged to lead by *example*.

Meritxell Draper Font, Jordi Gràcia Peiró and Toñi Segura Baeza. *ALLEM Federation*

Professionals are repeatedly required to take decisions on behalf of the people we care for, either because the individual concerned lacks the necessary capacity or because of the role of relatives who often, as they become older, assign "guardianship" of their children to the care services.

We would like to consider the role of care professionals, both care staff and managers. Organisations consist of people. If we are to look after those in our care, we must also look after those who work in our organisations. We must be passionately committed to change, reviewing not just our actions but the values and attitudes which underlie them. It is not easy to subject one's actions and attitudes to such review. We may feel attacked, monitored, criticised or questioned. And if this is the case then we don't want anything to do with it.

In addition to explaining functions, the induction process for new members of staff must include values or attitudes. It is not just a question of what is done, but also of how and why it is done. We tell the people who work in our organisation that the aim is not to shower the maximum number of residents within a given period of time, but rather to accompany the resident during the process of taking a shower as if he or she was the only person who needed to take a shower, showing respect, protecting privacy, promoting autonomy and on the basis of a human relationship, not in terms of "productivity". It doesn't require anything spectacular, just starting every decision we take, every action we perform with the question "why?"

During the workshop, somebody commented that it is direct care staff who "have all the power", because they are the ones who are closest to the person being cared for and spend most time with them. Who has granted them this power? And how has it been granted? When he or she became a member of our organisation? Have we spent time explaining things to them, teaching by example, ensuring that they were accompanied by staff who had already been trained, or explaining which attitudes are permitted in our organisation and which are not? Professionals should feel empowered, but we need to be careful to ensure that this is based on prudence, consensus and understanding. If a person is to make changes, he or she must first understand what these changes are. Everyone is afraid of change, while what is familiar makes us feel secure. At bottom, we may also believe there is no need for change if things already work and there are no "complaints" from others. This brings us back to the idea we discussed earlier, about looking at things from another perspective, looking at things from the perspective of the person on the other side, the person being cared for.

Eugènia Llovera and Anna Santaulària. *Atendis Private Foundation*

Care professionals need not only to interpret or decode the expressions but also to understand the actions of the service user. This comprehension necessarily involves doubt, and questions as to the meaning of the action. And this questioning must occur again and again. Otherwise, the action becomes a signifier capable of transmitting only one meaning, as a result of which communication is limited. The ethical dilemma arises when the other (care professional, relative) speaks for the user, assuming that we know what the user really feels or needs.

Arantxa Uranga. *Assisted Institute Paulo Freire of Reus*

The care professional must feel that he or she belongs to an organisation. We must know the reason for performing our work. This means considering the ethics of service users, of the family and of the organisation. And this means fighting against depersonalisation and accepting that it is not enough simply to apply logic when interacting with people with mental disability.

As a result, we need to be involved, and to take a "good" attitude to our daily practice. But this attitude, which I personally believe is very difficult to measure (unlike Pablo Hernando, who argued that this is possible), is also affected by three circumstances which make it difficult to maintain:

- lack of professional training, making it difficult to offer the quality of care we are obliged to deliver
- financial discrimination against those who work in this sector as compared to other sectors
- "unfair" social and administrative recompense for efforts, where those involved suffer from insecurity, obstacles and discrimination.

Another point is that practice and reflection should feed into and support each other. This is why analysis is important, and this requires both time and organisational restructuring which often has budgetary implications. Despite these obstacles, I believe that space for reflection is a necessary tool in achieving good practice.

Strategies for addressing values in our organisations

Meritxell Draper Font, Jordi Gràcia Peiró and Toñi Segura Baeza.
ALLEM Federation

Being able to take part in a workshop like this gives us the opportunity to enjoy a privileged space for reflection of the sort which is essential if we are to understand our care services.

This workshop, organised by the Víctor Grífols i Lucas Foundation, confirms once again that we are on the right path. The presentations have provided a valuable expert perspective on what we do.

In Lleida, over a year ago, we decided we needed to create this kind of space. We needed a structured space, where reflection would not be overwhelmed by the urgency of intervention and of "doing", as usually happens in our working environment. We wanted a space where we could invite experts who were external to our organisations to help us to describe, share, think about and reflect upon why we do things and whether there are other ways of doing them. Why do we take some decisions and not others? What lies behind our decisions and interventions?

A little over a year ago we established our space, a space created out of necessity, with passion, in the conviction that not everything has been done, and as the expression of a desire to grow and develop. The space has ten members with different profiles and drawn from different professional disciplines; six of them work in the organisations which belong to our group, and four are external members. The composition of the group provided added value, not just because of the presence of the four external members, one of whom acts as chairperson, but also because the members who work in our sector come from different organisations and have different positions and responsibilities. This has had the beneficial effect of ensuring that contributions, while made on the basis of mutual respect, represent different perspectives and are not inhibited by considerations of power and seniority. Different ways of doing things raise different concerns. Practice which has worked well for a long time or ways of doing things which some organisations do not question while others do have helped to promote reflection about what we do and why we do it.

In our space, we have addressed three sets of issues: individual cases, training and protocols, all of which are treated with the same importance. In the beginning, the cases which concerned us were the ones which had caused greatest disturbance, often associated with the higher-functioning individuals who tend to be the ones who challenge established practice. However, as time went on, we began to focus more on basic issues of caring for people with disability. We considered situations which do not create a disturbance but where it is possible to add value to the relationship and the care, something which is essential when caring for the most vulnerable service users, people who often communicate through behaviour, whether disruptive, uncooperative or simply by being inexpressive. We need to attend to such manifestations and ensure that our perspective is inclusive.

The aim of our considerations is to conduct a critical and self-critical review of the daily decisions taken in our care services. We share with today's speakers concern at the danger of 'imposing' the creation of spaces for ethical reflection. Such spaces must arise from the need, interest and passion of care professionals, not as an obligation imposed by a policy document. We are convinced, in the light of our own experience, that spaces for ethical reflection must be carefully structured both in terms of their working methods and their composition. Clearly, the expert member plays a vital rule, and if he or she is external to the organisation then this provides an additional perspective.

Ongoing training of members is essential. It would clearly be risky to put forward contributions, considerations and arguments on the basis of ethical ignorance. Otherwise, we will constantly find ourselves ending our interventions with the words, "Well, I don't know why we do it like that, we just always have."

We believe that we have made, and continue to make, slow, careful progress. It is now, after this period of exchanges, that we see the need to draw up a

good practice manual. At the start, this wasn't even something we had considered, we just wanted a place for practical discussion, rather than creating a space for well-intentioned theory with no real impact. Now, however, we are keen to draw up a good practice manual which summarises the basic aspects of the care relationship and interventions. In our sector we have undergone extensive training in therapeutic issues, and we have a range of tools which help us in our work with service users (music therapy, horseriding therapy, art therapy, occupational therapy, physiotherapy, aromatherapy, etc.). In the professional context, we have completed training about burnout, caring for the carer, teamwork, conflict resolution, etc. But where is the training about bonding, relationships, values, ethical aspects and attitudes? We believe that drawing up a good practice manual will help us address these issues. To do this, it is essential that we draw on the critical and self-critical perspective we mentioned above, but it needs to be more than just a dossier which is more or less comprehensive. How can we incorporate the latest developments on working with people with disabilities? How do we disseminate and apply this knowledge? Who will monitor its implementation, resolve doubts, record concerns or provide an example? How is it to be monitored? How can we evaluate it? What do we need to do to ensure that the manual is a living, working document which serves to constantly review practice and which in turn is constantly updated? Much remains to be done.

Often, when seeking to make changes, we try to incorporate *everything* necessary to ensure success, we focus more on outcomes than on the process, and we want large changes without appreciating small steps. We are convinced that it is possible to incorporate ethical reflection (that is, the process which occurs in the framework of the space for ethical reflection) in the existing structures of organisations: in meetings, monitoring and working documents such as, for example, the working plan or definition of goals. It can also be incorporated into such processes as initial family interviews, the reception of service users and, naturally, in the induction process for new staff.

These are some of the issues which we think are important. Discussion of ethical considerations, or to put it more simply, the self-critical review of our decisions and interventions, is not something that can be done by a handful of people meeting from time to time. It has to be a way of working, and this means that there must be an implementation process which is neither arbitrary nor imposed and which is not governed by a written document. We are talking about a different way of doing things, which must be taught by example, not imposed from above. If we are to incorporate it into our work, we need to share, to explain our concerns and our difficulties, to understand and comprehend. We need to be able to explain to others why we have done something in a certain way, without worrying about being criticised or judged. In other words, the space for reflection must provide a possibility for growth, for review and for change, for interventions which are focused upon the individual nature of each service user. In some cases, this will mean prioritising the principle of autonomy, and in others the principle of beneficence, but we cannot look after individuals if our practice does not also entail looking after care professionals and the organisation within which they work.

The space for reflection must be used to draw up a strategic plan to 'sell' ethical reflection as a tool which supports, accompanies and facilitates our practice, and which enriches and refreshes it. We need to ensure that it fits with our daily work in a natural way, not as an artificial addition which we must constantly remember to apply. But just like a recipe, this requires certain ingredients: time, patience, a good helping of passion, plenty of good-quality training and, of course, the support of experts. We also need to be clear about what it is that we are cooking, noting and encouraging small changes and, finally, emphasising the process rather than the results.

This workshop organised by the Víctor Grífols i Lucas Foundation is one more step along the path which our sector has decided to follow, but it is essential that we continue on our journey because the people we care for deserve nothing less. However, if we are to be successful, we will need the support of experts and of organisations such as those which have organised today's event.

Maite González-Nicolás Cerón, Silvia Lobera and María Ángeles Ortega Reverte. *Grup Catalònia*

In our organisation we had for many years felt the lack of a forum for discussion and inter-professional debate, where we could set out and analyse our core and changing values, and to discuss and implement the values set out by the administration.

The starting point would be the following:

> "Any code of ethics must be based on a legal model and draw on case law." In this regard, the law protects people with mental disabilities in two specific ways:
>
> - The person with mental disabilities enjoys all the rights enjoyed by any other person. This is a fundamental right which takes precedent and is contained in the Spanish Constitution. No distinction is made between people with mental disability and others.
> - People with mental disabilities enjoy special protection from the Ministry for Legal Affairs.

This is the basic and indisputable starting point for deeper considerations which should give rise to specific day-to-day actions. Many of the issues considered by our ethical discussion group were also raised during today's seminar:

- An organisation's intervention model and working methodology must be designed by the organisation itself. The organisation is responsible for creating the means for implementing this model, and the basic principles of intervention cannot vary depending on who is on duty at any given time.
- We need to avoid a situation where service users are better dressed, have received less medication or engage in activities depending on the shift, care team, tutor, psychologist, doctor or nurse on duty or the unit to which they belong.
- Ethical dilemmas, problems and conflicts must be resolved in a responsible manner, seeking to involve the inter-disciplinary team, seeking a global resolution, and attempting to create the documentation needed to address similar problems in the future.

- We need to ensure the commitment of the guardians of the people being cared for, and keep them informed about what activities are performed with their relative or charge.

Taking this as our starting point, we considered the need to create a robust, internal regulatory system to help us resolve some of the issues described above while also providing a space where we could reformulate some more general questions with the aim of improving care for people with mental disabilities. It also demonstrated the need to reconsider some basic issues relating to current practice. Finally, it forced us to constantly review training plans for all staff with the aim of ensuring that those working in our service have a clear model of how to behave.

As Pablo Hernando has said, a solid regulatory system would consist, basically, of the following:

1. Creating a code of ethics which sets out the values of the organisation.
2. Creating an ethics committee with multi-disciplinary membership.

Going further, in addition to the role described by Pablo Hernando, we would define the functions of the ethics committee as follows:

1. Ensuring compliance with the organisation's basic objectives.
2. Ensuring changes to methodologies, organisation, activities, technology and other developments, the incorporation of new members of staff, etc. In sum, the design of new models of care which are consistent with the organisation's objectives.
3. Defining a system of values which links us to the rest of society and reflects democratic realities: inclusive, compassionate, self-directing and sustainable.
4. Defending the rights of people with serious and less serious mental disability by providing the help and support they need to achieve the highest possible quality of life.
5. Ensuring good practice with the aim of providing a high quality of service and, most important of all, encouraging everyone in the organisation to share the philosophy of quality working (*moving from doing the job to striving to do it well*).
6. Enabling organisations and families to work together in reaching decisions about how to understand and help the individual in the organisation's care.

Arantxa Uranga. ***Assisted Institute Paulo Freire of Reus***

The ethics we need must be:

- an ethics which seeks the truth
- a civic ethics which seeks justice, and "goodness".

This ethics is closely tied to dignity. And in the world of disability, dignity is closely linked to vulnerability and self-determination. As professionals working in this sector, we need to be alert to the danger of "denigration". We cannot allow the vulnerable to become the abused. We must know how to include service users and their families, and to guarantee quality and excellence.

At the same time, the ethics of our organisation is characterised by the explicit recognition of values which may differ from those held by wider society. The aim may be to improve competitiveness or legitimacy, but they may also need to fill the gaps left by legislation, because the law is not always sufficient.

Ethics committees must be consultative and interdisciplinary in their approach to analysing ethical conflicts relating to care and helping to improve the quality of care. They should be independent of management, even though management must also follow the code of ethics. It is also important that they are proactive and enjoy the support of care professionals.

Codes of ethics set out the values which underpin group culture, they perform an educational function and help to identify standards of behaviour which should be met.

With regard to people's basic rights, a number of considerations have been identified as arising from practice:

- On the one hand, everyone agrees with the aim of promoting human potential, within the limitations of the service user and those imposed by resources (once again).

- On the other hand, on the basis of our knowledge of the realities of caring for people with severe mental disability, there are questions regarding the sanctification of certain principles. As a result, one can question the prioritisation of the principle of self-determination over that of safety, or the principle of normalisation over that of individualisation.

Having the opportunity to discuss doubts and concerns and to question words or concepts which are often little more than empty fads is always valuable.

Finally, I believe that everyone here today agrees on the usefulness of drawing up some kind of code or protocol which sets out the minimum principles or values which characterise each institution. We need to develop strategies to move from theory to practice, understanding *ethics* as intimately linked to *action*.

List of participants

Speakers

- Begoña Román
  Professor at the Faculty of Philosophy at the University of Barcelona
- Pablo Hernando
  Psychologist and Director of the Centre for User Services at the Hospital Parc Taulí

Coordinator

- Josep Ramos
  Director of Care Planning and Coordination for Mental Services at Sant Joan de Déu

Invited specialists

- Pilar Bermúdez
  Psychopedagogical Coordinator at the Vallparadís Foundation
- Elisenda Bernatallada
  Workshop Manager at the Hermanas Hospitalarias del Sagrado Corazón de Jesús
- Marc Antoni Broggi
  Vice-president of the Víctor Grífols i Lucas Foundation and chairperson of the Bioethics Committee of Catalonia
- Victòria Camps
  President of the Víctor Grífols i Lucas Foundation
- Montse Codinachs
  Technical director of the Sant Tomàs-Parmo Association
- Meritxell Draper
  Director of the Research and Training Department of ALLEM Federation

- Maite González
  Director of Montserrat Montero Institution (Grup Catalònia)
- Jordi Gràcia
  Coordinator of Nursing at Sant Joan de Déu (Lleida)
- Eugènia Llovera
  Director of Can Rull Center (Atendis Private Foundation)
- Silvia Lobera
  Psychologist at the Montserrat Montero Institution (Grup Catalònia)
- Jordi Mir
  Director of the Julio Payas Residence and Day Centre for People with Serious Learning Difficulties (Santpedor)
- M.ª Ángeles Ortega
  Coordinator of the Sever Mental Disabled Center and of Grup Catalònia
- Anna Rafanell
  Technical director of the Hermanas Hospitalarias del Sagrado Corazón de Jesús
- Marisa Ràmia i Ràmia
  Director of the Pinya de la Rosa Residence (Aspronis Private Foundation)
- Dominica Rodríguez
  Director of Hogar Santa Maria (El Maresme Foundation)
- Beatriz Sánchez
  Nurse at the Hogar Santa Maria (El Maresme Foundation)
- Anna Santaulària
  Director of Centro Arimon (Atendis Private Foundation)
- Beatriz Sanz
  Psychopedagogical Coordinator at the Vallparadís Foundation
- Arantxa Uranga
  Social Worker at the Assisted Institute Paulo Freire of Reus
- Montse Vilella
  Technical director of the Villablanca Private Foundation

Publications

Bioethics monographs:

21. *Ethics in care services for people with severe mental disability*
20. *Ethical challenges of e-health*
19. *The person as the subject of medicine*
18. *Waiting lists: can we improve them?*
17. *Individual good and common good in bioethics*
16. *Autonomy and dependency in old age*
15. *Informed consent and cultural diversity*
14. *Addressing the problem of patient competency*
13. *Health information and the active participation of users*
12. *The management of nursing care*
11. *Los fines de la medicina* (Spanish translation of *The goals of medicine)*
10. *Corresponsabilidad empresarial en el desarrollo sostenible (Corporate responsibility in sustainable development)*
9. *Ethics and sedation at the close of life*
8. *Uso racional de los medicamentos. Aspectos éticos (The rational use of medication: ethical aspects)*
7. *The management of medical errors*
6. *The ethics of medical communication*
5. *Problemas prácticos del consentimiento informado (Practical problems of informed consent)*

4. *Predictive medicine and discrimination*
3. *The pharmaceutical industry and medical progress*
2. *Ethical and scientific standards in research*
1. *Freedom and health*

Reports:

4. *Las prestaciones privadas en las organizaciones sanitarias públicas (Private services in public health organizations)*
3. *Therapeutic cloning: scientific, legal and ethical perspectives*
2. *An ethical framework for cooperation between companies and research centres*
1. *Social perceptions of biotechnology*

Ethical questions:

2. *Sexuality and the emotions. Can they be taught?*
1. *What should we do with persistent sexual offenders?*

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