Autonomy and Dependency in Old Age

Monographs of the Víctor Grífols i Lucas Foundation 16

FUNDACIÓ
VÍCTOR
GRÍFOLS
i LUCAS

ISBN 978-84-692-0782-6
Edita: Fundació Víctor Grífols i Lucas. c/ Jesús i Maria, 6 - 08022 Barcelona

Autonomy and Dependency in Old Age

Monographs of the Víctor Grífols i Lucas Foundation 16

CONTENTS

Page

PRESENTATION

Why do we need to reflect upon the autonomy of those who are elderly, particularly when they suffer from limited functional capacities? Such reflection becomes necessary when we consider the fact that this reduction or loss of functional capacities in turn entails reliance on the assistance of others, changing the relationship of interdependency which existed prior to this reduction. For many elderly people, this assistance is frequent rather than occasional and is not restricted to a few specific situations or activities: in other words, the need for help affects their daily life and on each occasion their autonomy is affected, either for better or for worse. At the same time, the impact of this reduction in functional capacities may vary from activity to activity, and will be influenced by the context in which the individual lives his or her daily life. As a result, the situation of every elderly person is unique. This individuality –which is the product of each person's biography, their past and present relationships and interests, how they cope with problems– means that people with similar levels of dependency can have very different experiences and that each person's network of interdependencies is different. In short, in my opinion the autonomy of elderly people with functional limitations is a key issue for societies struggling to adapt to ageing and longevity.

The contributions of Bernadette Puijalon, Josep Vila and Moisès Broggi offer us different perspectives, drawn from the fields of anthropology, applied psychology and personal experience, respectively. These perspectives complement each other. Reading these accounts and considering the connections between them clarifies the range of issues to be taken into account when considering autonomy, and will stimulate new questions.

Mercè Pérez-Salanova

Autonomy and Old Age:
A Cultural Context, a Political Approach, a Philosophical Proposal

Bernadette Puijalon

The Cultural Context: Old Age Viewed as Decline

I will start by considering the cultural context of ageing, focusing on three key points. Firstly, while the ageing process is a law of nature, every culture has its own interpretation of this process. Our western societies view the life cycle as an ascent, followed by a plateau, followed by decline, while other societies (some African communities, for example) see it is a succession of rising terraces by which the elderly person becomes a «complete man» who has gone through all the experiences of life. So, of an old man who is hard of hearing, they may say, «He is so great that our words cannot reach him.» In other words, these societies offer a social compensation for a biological deficit. But we must be wary of idealising Africa. There is no link between how a society represents each of the stages of life and the treatment which individuals receive. These societies, despite their positive vision of ageing, do not have the economic resources to look after their elderly. By contrast, our western societies, while idealising youth, also impose harsh economic conditions upon the young, and although so much has never been done before for the elderly, old age remains a source of fear and rejection. This paradox, then, provides the context for our work.

Secondly, in our society it is imperative to «remain young» if we are to adapt to a world in which technology changes faster than we do. (If I want to see most of the technological objects which surrounded me in my childhood, my only option is to visit a museum, and the same is true of today's 20 year-olds if they want to see the game consoles they used a mere 10 years ago.) Time is an adversary which must be vanquished. «Time which, as always, is not visible, in order to become so seeks bodies and, wherever it finds them, takes possession of them so that it may use them to show its magic lantern»[1]. But in this case, too, a paradox arises. In order to remain young, to continuously adapt, to change everything, to relive every experience, there is one thing which cannot change: the body must remain young, fit and dynamic and this,

1. Proust, Marcel. 1954. *Le temps retrouvé.* Paris, Folio Gallimard.

of course, is impossible. Man records himself during the passage of time, and is an irreversible incarnation, as the philosopher Jankélévitch said. In our societies, an old man is not rich because of all he has experienced, but poor because of what is left to him to live.

Thirdly, old age is not a single category. For many years, the biological marker of age – fatigue of the body – was in harmony with its sociological marker, retirement. However, these markers are now out of synch. While the biological limit has been pushed back by improvements in public health and medicine, the sociological limit has been brought forward and it is possible to find oneself excluded from the labour market having become obsolete at the age of fifty. As a result, we are socially old at an earlier age and biologically old at a later one. It is important to bear these three points in mind if we are to understand the political context.

The Political Context: Managing Worn-Out Bodies

An Essential Perspective: The Intimate One

How do people face advanced old age? Most of the time, in a state of anguish. I will quote François Jacob, winner of the Nobel Prize for Medicine: «What is impossible to forget is the fear of being afraid. […] The impossibility of avoiding impotency. And also the terror of being dominated like a child, of being manipulated. The obsession with becoming a different being, of thinking differently and even of ceasing to think at all. And afterwards, the nightmare of having to suffer, of people doing things to one and being unable to react, to explain oneself, even to ask. In sum, the spectre of becoming a vegetable.»[2] In other words, of becoming the object of care, a person who depends upon others, not only in the performance of activities of daily living but also to the extreme of others deciding what is best for one.

2. Jacob, François *La statue intérieure*. O. Jacob, 1987

The Perspective of Families

Here we encounter rejection and denial. I recall a text by the writer Pierrette Fleutiaux:

> «I wish my mother could grow old without ageing, that she could grow old the way people do in magazines or in flattering portraits or in insurance company adverts. That her old age was nothing more than another way of being, different but equally powerful, that her arthritis did not prevent her from wearing fashionable shoes (with lower heels if required), that her high blood pressure did not prevent her from eating well (light diets accepted), that her dizzy spells were compatible with cruise trips for pensioners (some adjustments accepted), that her mind (a degree of slowness accepted) would continue occupying itself with all those annoying little problems that adults deal with, tax declarations and the rest, and that her memory (a little weak) would continue to be the custodian of the family archives and the museum of our past. […] I don't want my mother to grow old.»[3]

One might expect that the political response would seek to combat these fears, this denial, but this is not the case. On the contrary, it amplifies and exacerbates them and generates what I refer to as a diabolical operation.

A Diabolical Calculation

To explain the political approach, I will use the metaphor of the mathematical operation of division. Let us view society as the number being divided and the expression «to stay young» as the first divisor.

Seniors, the elderly young, are told by our society «to stay young». No account is taken of age. «You will be integrated if you keep yourself young,» if you struggle against time and its ravages. (This is what, in France, the first major report on social policy with regard to old age, the Laroque report of 1962, advocated, in which one could read: «The elderly must keep themselves young.»). In this division, the product is the third age, active pensioners, but there is also a remainder, the fourth age, those who do not manage to remain

3. Fleutiaux Pierrette. *Des phrases courtes ma chérie*. Actes sud. 2000

in this golden age and instead enter advanced old age, where everything becomes negative. These are the ones who, rather than going «to Majorca in jeans» go «to Lourdes in slippers», to repeat the contrast drawn by a journalist at *Le Monde*. This is when these old people will be told they must be wise.

This brings us to our second divisor: «Become wise,» as the elderly were told in France in the second major report on social policy on old age, the Lion report, in 1981. This proposes a logic of compensation expressed in a dynamic of acquisition: «You may be losing faculties, but you can compensate for this by becoming wise.» But in both cases, the conditional prevails: «You will be integrated *if* …» This is the same law of continuous progress which declassifies and penalises all those who, in one way or another, decline.

As is logical, integration based on the identity of positive values creates a remainder, a remainder which does not carry any of the proposed values, a remainder which can only be treated. A political programme which seeks to resolve the question of old age with an arsenal of expensive measures, reasoning in terms of care and financial cost, is literally a diabolical operation, understood as separation, division.

Discrimination against the elderly, feelings of shame, is exercised naturally against those crazy old people, those King Lears, who have been unable either to keep themselves young or to become wise. For this «remainder» the only issue is how to resolve the problem of the care they require.

When a society analyses old age in terms of losses and deficits to be corrected then this becomes a social disease –dependency– which requires specific actions to be taken. Using assessment tools, managers decide how to allocate assistance and what resources are required: visits to geriatricians, medicalised institutions, etc. This logic follows its inevitable course and leads to the issue of the cost of this dependency, reinforcing the overwhelming emphasis on representing the elderly in economic terms. The practical consequence is the danger of technification and dehumanization. «That which power cannot comprehend, it measures,» in the words of the writer Jacques Attali.

At present we «manage worn-out bodies». How many worn-out bodies do we have? How worn out are they? What should we do with them? How much will it cost? In the absence of any understanding of how to integrate ageing into our society, we manage it.

To contain such a 'costly' phenomenon the care of the elderly is delegated to specialized professionals. And these professionals then find themselves at the heart of a contradiction, with an increase in the culture of outcomes: «we entrust our elderly to you, don't let them die.»

We run the risk of imprisoning the elderly within concepts such as fragility, dependency, incapacity, vulnerability, need and so on. To escape from this reductionist vision, I believe it is necessary to return to philosophy and to address other concepts such as autonomy, accompaniment, exchange and the like.

The Philosophical Proposal: Autonomy–Dependency–Independence

There is something surprising here. Why is dependency contrasted with autonomy and not with independence? In fact, we need to consider three concepts, not two, and doing so provides a fresh perspective on the meaning of autonomy.

How we View Dependency

A deeper consideration of 'dependency' uncovers both the ambiguous nature and the richness of the term. Etymologically we can identify an evolution in the meaning of the word from the Middle Ages (when it first appears) and the Renaissance. During the Middle Ages the word *dependency* appeared in a context of great insecurity. In this dangerous world, an isolated individual was unable to ensure his survival and had to establish links with others. The best example of this is the dependency established between a feudal lord and his vassals: two people who depended on each other, thereby creating the ties

which bound them together. Dependency is a form of solidarity. The first meaning of this word retains this sense of a link, a correlation, of interdependency.

By contrast, in the second meaning, which developed during the Renaissance, when security had recovered, dependency only expressed a relationship of subjugation, of submission. The link became a chain, and solidarity became slavery. One notices its weight rather than its benefits. In other words, from the outset dependency has been a complex phenomenon, which inevitably entails both negative and positive consequences. Solidarity, when expressed in terms of dependency, is more concerned with the reality of need than with the utopia of liberty. Dependency is not, then, a state but rather a function of living beings. A function which varies during the course of one's life.

For the sociologist Albert Memmi, «Dependency is a three-cornered relationship: there is the dependent person (the one who has a need), the provider (who responds to this need) and the object of this provision. The essential element of dependency arises between the person who asks and the one who gives. One can depend upon another person, but also on a substance (the drug), a belief, etc. Everyone enters into multiple, mutual dependencies, the majority of which are experienced as a form of solidarity or reciprocal dependency: I depend upon the affection of my friends, and they depend upon the affection which I give them back.

Autonomy

The etymology of the word comes from the Greek *auto nomos* (he who is governed by his own law). But we must distinguish between the following two definitions:

Functional autonomy is the ability to perform all one's activities of daily living for oneself: getting up, getting dressed and feeding oneself. When gerontologists talk of loss of autonomy, they are generally referring to functional autonomy.

But just as important is *decision-making autonomy*, which refers to the management of the individual's dependencies. This is the meaning which corresponds to the term's etymological roots. Preserving this decision-making autonomy is one of the principal objectives of any life project and is an issue we will return to later.

According to the sociologist Edgar Morin, «Any human life is a mesh of unbelievable dependencies. Of course, if we do not have the things we depend upon then we perish; this means that the concept of autonomy is not an absolute one but rather relative and relational. I do not mean that the more dependent one is, the more autonomous one is. There is no reciprocity between these two terms. I mean that autonomy cannot be conceived without dependency»[4]. By becoming aware of one's own dependency, one transforms it: one moves from the idea to the event.

For years I have been completing measurement tables for myself, because it is one thing to say «you are dependent» and quite another to say «I am dependent». Do you think I am autonomous? Is it so clear? The table offers the following options regarding memory: 1. Normal memory. 2 Memory subject to some gaps. 3. Memory subject to numerous gaps. 4. No memory. In all honesty, I tick box no. 2. A table regarding mood: 1. Stable mood. 2. Mood subject to some variations. 3. Mood subject to numerous variations. 4. Incoherent mood. Which box would you tick?

Dependency–Independence

Starting with the stoics, philosophers have explored the link between dependency and independence. Stoicism rejected any uncontrolled dependency and proposed an ideal of wisdom for individuals, who should concern themselves solely with what they could control and reject everything else. He who freely controls himself does not react to the setbacks of the external world. He frees himself of all earthly needs and possesses to the full that virtue which Seneca calls «constancy». This is the quality of the subject who exists for himself on

4. Morin Edgar. *La méthode*. Seuil. 1976.

a stable and lasting basis, a subject who does not change and who does not experience any need which he cannot satisfy for himself. Free of any ties, he can dedicate himself to the pursuit of the only good worthy of desire: the supreme Good (not all stoics give the same definition of this).

Let all those who are independent raise their hands! As far as I am concerned, I would think very carefully before doing so! Based on this hypothesis, there is no way of valuing dependency. This ideal has dominated a whole style of education, and common sense dictates that independence is superior to dependency, that it is typical of a mature, happy, free individual. In some societies (particularly oriental ones), old age is experienced primarily as the epoch of indifference and, therefore, of the highest level of wisdom.

How can we speak at the same time of an autonomy which is based on dependency, and of an autonomy which is the result of independence? Must we enclose ourselves within a limited pragmatism or, on the contrary, escape into an abstract idealism? Neither one nor the other. The pairing dependency-independence can only be understood from a dialectical perspective: each term corresponds to an aspect of life, and the contradiction is resolved in a third term. For biologists, to survive, living beings must act upon their dependencies in order to safeguard the «constancy» of their inner existence. At the beginning, independence as a myth; the myth of paradise.

This is the good which we have now lost, which ceaselessly torments our conscience; this universal myth, a state of perfect and ideal liberty, functions as an abstraction and motivates the search for liberty and identity of each and every one of us. Birth, in all its radical nature, denies perfect independence and inaugurates a present of multiple dependencies from which we never truly emerge, except upon our death.

Within this context, dependency, which is the only reality of which we can speak, acquires meaning as a result of where it comes from and where it leads towards. Dependency arises from necessity, and is not an ideal. The dependency which we need to live must be denied if we are to truly exist, and this denial is not a formal one but one which we experience as a constant struggle.

To affirm one's autonomy, to strive towards liberty, to establish one's own law, one must undergo it and experience it in all its forms to overcome it. It is a terrible challenge! A complex and arduous life path.

Dependency is also the place where the future of every individual is decided. For health professionals, the issue is not how to help with a dependency experienced as a misfortune, but rather to accompany the individual to the limits of the possible along the path of (decision-making) autonomy and, at the end, of independence (and so death).

I will quote geriatrician Dr. Guy: «Why, due to tragic indifference, is it necessary to entrust to trained, equipped and pressured technicians, exhausted lives, worn-out bodies and hearts yearning to be granted just a little time?»

We are a long way from the management of worn-out bodies to which I referred above. We therefore need to consider in greater detail the work of professionals. What is their role in preserving the autonomy of the elderly? I would argue that we need to move from a logic of «taking care» to a logic of accompaniment.

Old Age and Autonomy: From a Logic of «Taking Care» to a Logic of Accompaniment

When we talk of accompaniment we do so in the context of a relationship. This is a relationship between people who are at the beginning strangers to each other, and this relationship occurs within an institutional framework, codified by social policies and financially sustained by the national collective. A relationship which is viewed, in most cases, as forced, imposed by circumstances.

The elderly person who is unable to look after himself to perform the activities of daily living must have recourse to external help. The risk is that this external help is not satisfied with performing or helping to perform activities of daily living but rather, at the same time, appropriates the autonomy of the individual, deciding what is good for him.

I will take an example from Shakespeare's *King Lear*, which I referred to a moment ago. When this old king asks his daughters to respect his wish to retain a hundred knights, they respond: «O, sir, you are old. You should be ruled and led by some discretion, that discerns your state better than you yourself.»

The text remains full of relevance. For example: «Mum, you live on the fourth floor with no lift. You can't do the shopping any more. I'll do it for you, me, your loving daughter. But your daily chocolate cake is going to have to finish, it's not good for your health, you can only have it on Sundays. I'm deciding it for your good, mum.» Here I am taking the role of the daughter, but I could also have taken the role of the professional carer. Care frequently implies the theft of (decision-making) autonomy.

We understand that terms like «take care of» and «assistance» denote an unequal relationship between the helper and the person being helped; in sum, a relationship of domination, as we have already mentioned. Why should we prefer the term «accompaniment»? And, to start with, why this interest in words? Anyone with a little experience of social action can observe how such action tends to drift, to become technical, or to become fixed in the form of a programme, to run out of steam and to lose its meaning. Reflecting upon words allows us to rediscover the original meaning, the original impulse.

What definitions of *accompaniment* should we retain? In social action, it is usually defined as follows: «Accompaniment consists of seeking personalized help in managing a delicate situation.» With this definition, we are approaching familiar territory: the notion of help is a classic element of social action; the originality comes from the emphasis on the person seeking the help. The strong point is the word «personalized». However, we require a «made to measure» rather than an «off the peg» approach, not a programme made to suit everyone and, therefore, nobody, but a strategy adapted to all. As a result, however interesting this definition may be, it is not so novel that we should spend an excessive amount of time on it.

The etymology of the term *accompaniment* is a more fruitful source of inspiration. As is often the case, etymology opens up wider horizons than the definitions used in social contexts.

- *Accompany:* The verb means «to take as a companion», and then «to join with», especially in order to undertake a shared journey.
- *Companion:* Composed of *cum* (with) and *panis* (bread).

Let us note the notion of movement: accompanying involves joining with somebody in order to go where he or she is going. Assistants are young, and the young do not know what old age is. Or rather, they have an intellectual understanding of it, but have not yet lived through this period. Accompanying an old person, then, is different from accompanying a child, because it involves accompanying somebody who is experiencing something of which you have no experience. And we should also bear in mind that, while the elderly have experience of life in general, they discover what it means to grow old on a day-by-day basis. As we can see, the issue of accompaniment is a delicate one in which the one-eyed are helped by the blind.

Getting started means accepting one's transformation, allowing oneself to work on the deepest elements of oneself. Accepting that weakness feeds strength, poverty wealth, and old age youth. It is an adventure, understood as a «set of activities, of activities which are risky, innovative, and to which we assign a human value». The notion of chance, of the unforeseen is important. Daring to act involves taking a chance.

This also implies the notion of exchange. In a care relationship, one person gives and the other receives. Using the logic of anthropologist Marcel Mauss, this is clearly an unequal relationship, indeed one in which the *Magister* (the powerful) exploits the *minister* (the weak). Mauss's third obligation is the obligation to return, to re-establish equality, created by the exchange and the bond. It is necessary that a person who is accompanying another should agree to enter into a genuine relationship, based on listening, respect and exchange.

Specifically, I believe that accompanying someone on the path of autonomy means *taking the word of the elderly into account*. However, affirming the primacy of the word gives rise to certain objections:

- The word is contradictory: the person who expresses his desire depicts a landscape which differs absolutely from that of the rational dis-

course of the planner. These needs and desires emerge in accordance with a very «disordered» order, as it is only the individual who holds the key.

- The word is located in the world of emotions: an external, distanced observer who is familiar with the overall situation is better placed to assess that situation than the individual who is immersed in its emotional ramifications (remember King Lear).
- The word has no real utility: much of what is said is banal and lacking in importance.

At the same time, it is not easy to implement this principle of listening. There is a gap, frequently denounced by professionals themselves, between the principle and the reality, and there are many obstacles to its implementation:

- What can be done with people who no longer speak or whose declarations are incoherent?
- Why and how can we promote the word among those generations who are not accustomed to express themselves freely?

There are also other registers where there is reason to take the word into account.

Evidence

Attempts to take an objective approach are a logical response to contradictory evidence. However, it is hard to find something more truthful than those scattered words which are never closed or final but very much the opposite, always open, and which are constructed and deconstructed to the rhythm of events. The first register is a form of knowledge, while the second is a search. Reducing the elderly person to a mere object of care entails discrediting the existential experience of ageing. By contrast, listening to him means granting this experience a renewed legitimacy.

Critical Value

The elderly possess a genuine power of opposition, even if it is only to oppose a register which is excessively ordered and rational. Social action for old age is established within the framework of a predetermined organization, such as a programme. Constructed on the basis of multiple situations, this programme seeks to identify constants and translates them into universal rules of action, privileging the quantitative. It does not accept improvisation, and fears randomness. Individuals must enter this programme «ready to care». But the elderly express their wishes «made to measure», the longing to have their specificity and singularity recognized. They say how uncomfortable they find the suit they are being offered. And so they force the designers to insert an element of uncertainty into the analysis and the action; these are the words which bring innovation. These are the ones which force a regular reconsideration of what the work involves.

Consideration of Autonomy

The words of every elderly person sketch out the landscape of his autonomy, an autonomy which refers back to the literal and demand sense of he who establishes his own law. Only he who insists upon formulating his experiences, giving them form, and communicating them is a subject. And in doing so he is less of a «burden». He takes the reins of his life and constructs a «savoir vivre» which is more effective than any artificially created management tool. By contrast, it is he who abandons this auto-referential word who «is a burden» and an «object» of care. Words sharpen the objective focus. Intimate understanding of a situation can tell us more about a group than the best statistical analysis. When describing her professional career, every carer also highlights it with the encounters which have marked her and which have helped her progress. To be effective, knowledge must take a human form.

Having said this, listening to the word of an elderly person does not mean obeying the imperative to tell him everything, with a transparency which is both suspect and unattainable. Before growing into this sort of dialogue, the

word is born in the interior, in that which one says to oneself. Sometimes, silence is more eloquent than words, particularly in the register of the emotions.

Accompanying Old Age is Accompanying Disassociation

There is a specific way of working with elderly people which is that of accompanying *disassociation*. This involves accepting that not everything can be repaired or reconstructed. This is the disassociation which Erik Erikson spoke about when he was over 80 years old: physical disassociation (the body weakens), psychic (one's memory fades) and social (people of the same age die). Accompanying is, then, accompanying in the work of ageing.

Two situations arise. There are those who age asking themselves, «What is happening to me, here, now?» This is a work of comprehension. The other part of it corresponds to the external situation, and is a search for explanations rather than for comprehension. The flow between these two situations is a potential source of reciprocal enrichment. He who grows old teaches the person who is accompanying him. And the companion may give clues to aid this comprehension and, above all, seek to help provide the most bearable setting in which to live one's old age. Learning and enriching oneself is one of the means the professionals have at their disposal to combat disillusionment with their work.

Here we reach the second definition which dictionaries give to the term *accompaniment*, the specialized musical sense which appears in the 15th century: «To play an instrument at the same time as the voice or another instrument takes the principal part». In other words, one can walk «next to», one cannot walk «in place of». You can accompany somebody during ageing, but you cannot age «in place of» somebody. Once again, autonomy.

Here accompaniment takes the form of acceptance. There is no point following somebody who is lost in a wood merely to become lost as well. It is better to remain on the path, ready to extend your hand, as the philosopher Marcel Légaut argued. At the age of 88 years, talking about a woman in an old peo-

ple's home who had given up hope of a life which repeated itself day after day without respite and said «I'm no use any more, I want to die,» he said, «There is a clear contradiction when, out of absolute submission to what one feels, to what one knows, to what is imposed from without and from within, a person claims to be an insubstantial cloud, while making this claim with the confidence of someone who knows what they are. We prefer to subscribe to this contradiction to escape the contrary assertion, which proposes the fundamental reality of man despite everything which denies this, which makes it unreal or even unthinkable.»[5]

Let us return to the musical metaphor. While I have tried to take this as far as possible, because what makes metaphors interesting is precisely this capacity for extension, I recognize that there is also the possibility of a mismatch, because the image retained does not quite fit the mould and we run the risk of it overflowing. As we are talking about music, I have asked who is the composer, the conductor, the first violin and so on.

With regard to the composer, I would like to be able to say that this role corresponds to each old person; but given how care is currently organised, I am tempted to respond that this role is filled by the public authorities, by the powers which provide the framework and the resources, in sum, those who write the score which everyone must perform. An orchestra is a very hierarchical institution, particularly a classical orchestra. In other words, the metaphor comes up against its limits. And so, rather than the classical orchestra, I prefer the jazz group, which performs a series of improvisations within a particular register, in our case the register of ageing.

To summarise, in the relationship between two people, the elderly person shows something to the person accompanying him, if the latter wishes to receive it, something which talks to him of the register of his philosophy of life and also of his own ageing process. An African proverb says, «If the young man's mount is swift, the old man's mount knows the path.»

5. Légaut Marcel. Entrevista (unpublished) with Pierre Babin. 1988.

Conclusion: From the Diabolic To the Symbolic

With this division we find ourselves in the realm of the diabolic. How can we pass to the symbolic, that is, to a vision which permits exchange instead of exclusion? Creating a place for old age necessarily entails the acceptance of age differences. It is by starting with an affirmation of difference that we enable flow and exchange. But not any difference, not that of the old body opposed to the young body, of the dependent opposed to the autonomous.

The difference to take into account is the experience of different stages of life. What flows and is exchanged between the young and the old is the inscription in time. If the old gives to the new the dimension of the past, it is the elderly person, and he alone who, with his many years, with his testimony of the length of life, opens the future to the young. At the same time, the old person reminds us that life is a journey: old age, as a limit to life, possesses in itself a symbolic value.

The growing number of old people can only lead a society which thirsts for modernity to focus once again on this crucial point where life provokes death; in other words it brings about the abandonment of the mythical site of absolute life, without limits, closed in on itself and, therefore, sterile. Because it is he who allows us to cross from one shore to another without claiming thereby to know the landscape on the other side, and because he talks not of the past but of the future, *the old man is the guide, the boatman*.

Old age is not the time when the lesser happens to the greater but is, as in other ages, a time in which the greater and the lesser come together, in this case the greater of the years and the lesser of the exhaustion. Ageing has nothing to do with a rarification of the self. However much wax there is, the height of a candle flame is always the same. One can, one must create a context in which the flame can burn high and bright. Accompanying is to warm oneself in the heat of this flame which raises itself alone, as the best justification for autonomy is the existential solitude of each human being who maps out his route crossing that of others: every life is a creation. In a human world, then, we go from the concept of autonomy to that of dignity.

Questioning Autonomy in People With Dependency:
Analysis of Situations of Daily Living

Josep Vila i Miravent

Introduction

The structure created by our public health and social services network to attend to the needs deriving from situations of dependency in old age is organised around various care settings. These settings become service provision centres, both at home and in specific centres. All of these centres share the same aim of offering support to people who suffer from some kind of dependency in the performance of basic and instrumental activities of daily living (BADL and IADL). This focuses very specifically on functional autonomy. It is assumed that the professionals who work in this environment have received specialized training which prepares them for this task. However, in care teams there is a great variety of training backgrounds, and some members, such as clinical or geriatric auxiliaries, have not completed any regulated training. The care team needs to have constructed a shared trajectory which enables its members to fulfil the mission which has been entrusted to them. In addition, in these settings –as in others– it is necessary to complement this training with continuous development, both through new training events and courses, and by developing experience-based learning which enables people to analyse their formal training in the light of practical experience, and to deal with unexpected situations. It is therefore a process which requires time and space for reflection. We need to feel that we have been prepared to deal with the conflicts which derive from functional autonomy, but also with moral and ethical conflicts.

Questioning Autonomy

We understand that all professionals accumulate a lot of experience from their practice, and this is as important as formal training. Often, the resolution of daily situations with people with dependency is based more on acquired experience than on training. The needs of people with dependency require us to take decisions –and therefore to act– in situations which are highly context-dependent and where subjective judgements play a major role. How has a particular action been chosen? What reasoning process was used? What determined the final decision? We will find a large number of factors

in the responses. For care settings and the professionals who work in them, the resolution of these situations is a source of unease and feelings of guilt, anger or frustration. This unease forces us to face the contradiction between our vision of professional practice and the reality of our working environment. Senge[1] defines this contradiction as *the creative tension* which becomes an opportunity for learning. For professionals concerned with ensuring best practice, this tension is unpleasant but inevitable. Analysing and reflecting upon the factors which contribute towards this tension can help us to improve our performance in new situations.

Johns[2] defends the development of a *reflective practice*, understood as a process of investigation in cooperation with a guide or supervisor, with whom the individual sets out, understands and analyses the contradictions of daily practice with the aim of resolving them. Johns proposes incorporating the concept of *reflective practice* in care settings and ascribing it the same level of importance as other interventions which enjoy prestige and whose usefulness we do not question, such as consulting with other health professionals or services as to the best course of action to follow.

Situation Analysis Methodology

Within the context of reflective practice, a method has been developed to analyse the ethical dilemmas which arise in care settings. The ethical map trail (Johns, 1999)[3] is the method I will use to present situations of daily living. The trail is an attempt to identify the different perspectives and contextual factors in an ethical decision. The professional can examine value clashes and power relationships existing within the unit, and which largely determine who takes the decision. Johns proposes the trail described below. His

1. Senge, P. 1990 *The fifth discipline: The Art and Practice of the Learning Organisation*. Century Business, London.
2. Johns, C. Unravelling the dilemmas within everyday nursing practice. *Nursing Ethics*, vol. 6, no. 4, July 1999, p. 288 (4)
3. Johns, C. Opening the doors of perception. In: Johns, C, Freshwater, D eds. *Transforming nursing through reflective practice*. Oxford: Blackwell Science, 1998: 1-20.

proposal is based on hospital settings: in this case, the vocabulary has been adapted to that of a care setting for dependent elderly people:

1. Frame the problem.
2. Consider the perspective of different people, starting with the auxiliary geriatric staff.
   - Identify the perspectives of others.
   - Confront your partial perspective (every perspective is a partial vision).
   - *Motivation.* What is best for the interests of the person, the professional and the organisation?
   - *Reasoning.* Pass from a partial to a general vision.
3. Consider which ethical principles are correct in terms of the best ethical decision.

   Tension: patient autonomy / professional autonomy.

   - Ethical principle: professional autonomy.
     Beneficence and malevolence: doing good / avoiding harm.
     Bear in mind: the best for the elderly person.
   - Ethical principle: autonomy of the dependent elderly person.
     Respect for the right to self-determination. Enable the person to take the best possible decision. Tell the truth / Obtain the truth.

   Tension: needs of the individual / needs of society.

   - Ethical principle: the general good.
     The needs of the individual are secondary to the needs of society in general or those of the social group.
   - Ethical principle: virtue and duty.
     Be correct / appropriate to the requirements of the profession. Professional ethics.
4. Consider what conflicts there are between perspectives / values and how these can be resolved.

5. Consider who has the authority to take decisions and act.
   - Autonomy / Authority / Responsibility.
   - Legitimate autonomy: the authority indicated in the job description.
   - Discretional authority: the authority which the individual believes he or she has.
6. Consider the power relations / factors which determine how the decision was taken and how action was implemented.
   - Decisions are not always taken on the basis of what is best for the elderly person or the family, but in terms of power and fear of punishment.

Ethical Map Trail, Johns, C. 1999[4]

Perspective of the elderly person or the family	Who has the authority?	Perspective of inter-disciplinary team
What conflicts regarding perspectives and/or values exist?	THE SITUATION / THE DILEMMA	What ethical principles arise?
Perspective of the auxiliary geriatric staff	What power relations affect the decision?	Perspective of the organisation and management team

4. Johns, C. Opening the doors of perception. In: Johns, C, Freshwater D eds. *Transforming nursing through reflective practice.* Oxford: Blackwell Science, 1998: 1-20.

Presentation of Situations of Daily Living

1. First Case: You Can't Leave!

The decision to leave the care home every day, despite the illness, is the object of general discussion.

Brief Biographical Presentation

Seventy-five year old man. Entered a public care home of his own accord. Divorced and with one daughter, he lived alone in his own home with the help of a family social worker and the supervision of his local social services centre.

XM has suffered from Parkinson's disease for 6 years. The illness causes difficulty in performing Basic Activities of Daily Living (BADL) and Instrumental Activities of Daily Living (IADL), principally with regard to mobility and personal care. To date no cognitive difficulties have been observed which affect his reasoning capacity.

XM has lived in Catalonia for over 35 years, although he is originally from the other side of Spain, where he still has some relatives. His family in Catalonia has broken all ties with him and he receives only occasional support from his only daughter. His ex-wife has informed the managers of the residential home that she does not wish to have any kind of relationship with him. His daughter explains that her father is very determined to remain independent, that he has always wanted to have things his own way, that he takes decisions on his own, and that he is difficult to get along with.

Brief Description of The Current Situation

This brief description provided by the daughter concurs with the way XM lives in the home. His behaviour is polite, he has few relations with the other users of the establishment, and does not allow geriatric auxiliary staff to help him perform BADL. The only services he uses are accommodation and maintenance. He spends most of the day away from the home, on personal business.

His problems with independent mobility and looking after his personal appearance are becoming more self-evident. XM has suffered several falls in the street in areas of the city which are a long way from the home, requiring the help of members of the public or the local police, who either take him to hospital for evaluation or directly to the home. Although he dresses smartly, he wears dirty clothes, causing concern among those caring for him. There are stirrings of general concern –the local police, other citizens, geriatric auxiliary staff, fellow users of the home, members of the inter-disciplinary team, the management team of the home– regarding the maintenance of his independence.

When he has been accompanied by the local police, when looking for his documentation, they have found him to be carrying sums of money in the region of €150 to 300.

XM says he is aware of his illness and the mobility problems it causes, but he plays down the risk of falling, or its consequences, rejects the help of others, and does not accept the offer of help of a volunteer to accompany him on his business outside the home.

The Dilemma

The dilemma which arises is how to respect his independence and his right to decide not to respond to the risk of a fall resulting in possible fractures and a deterioration in his health, in addition to the risk of falling victim to theft.

Analysis of the dilemma according to the methodology proposed in Ethical Map Trail, Johns, 1999

Trail: The Perspectives

The perspective of the elderly person: I have Parkinson's disease, but I have sufficient personal resources to take decisions and make up for limitations.

The other perspectives: these share the risk assessment: risk of fall and accident; risk of being a victim of theft or violence.

Map: Ethical Principles and Conflict of Perspectives and Values

Autonomy of the person (self-determination) vs. virtue and duty of the professional.

There is a conflict of perspectives in the analysis of risks and how to deal with them. Professional duty involves doing the best for the individual but his self-determination is threatened.

Map: Authority and Power Relations

The senior authorities are the director of the home and the elderly person himself. The team of auxiliaries, the interdisciplinary team and other members of the organization exercise their power when helping to negotiate a solution. The de facto power of the external actors (local police, citizens, hospitals) condition the director's assessment.

Proposed Solution:

1. To increase accompanied outings.
   Respecting his right to go out when he wants to, but making clear the need for support from another person to reduce the risk of accident.
2. To reduce as far as possible / prevent unsupported outings.
   To question unsupported outings. To demonstrate the mobility difficulties.
3. To evaluate with the elderly person his needs to conduct his affairs in person.
   To offer support for conducting these affairs, and to identify those issues which can be resolved from the establishment itself.
4. To provide documentation to the elderly person for use in the event of accident or necessity.
   To provide documentation regarding his situation in order to facilitate the job of those who offer to help: citizens, local police, hospital staff.

Perspective of the patient / the family Views Parkinson's disease as one more problem of the many he has faced in his life and thinks others should not be involved. Believes he is able to do what he wants without depending on third parties. The family believes he has always acted without common sense and that there is nothing to be done.	**Who has the authority to take the decision / to act?** The director of the establishment has been granted de facto guardianship of all the people who live in the residency. He is responsible for ensuring their physical and psychological well-being and that they are not the object of abuse regarding their property	**Perspective of the staff: interdisciplinary team** The elderly person's style of life must be respected, but with the support of others: relatives, friends or volunteers. They want to evaluate the possibility of hiring professional accompaniment services.
If there is a conflict of perspectives / values, how can these be resolved? Exercise the right to self-determination / avoid causing harm. Analyse with the elderly person the reasons for his outings, and agree days and times for these with the support of a third person.	**The situation / the dilemma** The independent lifestyle of XM is a threat to his health. We want to respect independence, but we have to look after his health and personal safety.	**What ethical principles arise?** *Professional autonomy* *Autonomy of the elderly person (self-determination)* *The general good (needs of the individual and society)* *Virtue and duty: professional ethics* Self-determination of the elderly person. Autonomy of the professional. Virtue and duty.
Staff perspective: geriatric auxiliary staff His current level of autonomy with regard to BADL and IADL is incompatible with the rhythm of life he wants to lead. The risk of falling is evident in the residential establishment.	**Power relations Factors which determine how the decision is taken / what action is taken.** Citizens, the local police and hospitals question the professionalism of the home.	**Perspective of the organisation / management team** Not intervening in the light of the observed facts raises questions about the quality of the services offered. The local police and those living around the home tell the organisation that it is not right to allow him to go out alone.

2. Second case: To Table and To Bed the First Time You're Called!

The decision to choose mealtimes and bedtimes challenges the organization's timetable.

Brief Biographical Presentation

An 80-year-old woman. Entered a publicly funded care home with her husband, aged 89, of her own accord. Have only one son, who has been decisive in searching for and accepting support. Although JM accepts that she agreed to enter the home, she thinks it was her son who took the final decision and says that she felt very influenced by his pressure.

JM suffers from mood swings, with times of the year during which her depressive symptoms intensify considerably. JM and her husband lived alone in a rented flat with the help of a family social worker, the supervision of the local social services and the constant intervention of their son. Upon admission, their son told us that they were in a state of abandonment, didn't keep regular hours, didn't look after the house, didn't eat properly and spent many hours in bed. A poor diet which doesn't meet her needs and which worsens his mother's risk of obesity. In addition, the son says he feels very isolated in his responsibility for maintaining his parents' well-being.

Brief Description of the Current Situation

JM refutes this perception of reality and believes that in their home they chose to live freely, without timetables or responsibilities imposed by others. She believes her son is exaggerating and has interfered with their lifestyle.

During the first two weeks in the home, JM believes that the services and rules of behaviour of the home do not fit with the way she wants to live, and asks her son to demand respect for her individualism. Specifically, she wants to be free to decide when to get up, when to eat, and what to eat. She wants to be allowed to have food in her room. Her son asks for flexibility with regard to food. He is positive about all the services but would like them to be

more flexible and is willing to sign whatever authorizations are necessary for us to allow her to eat what she wants in her room without having to use the general dining room.

The Dilemma

Two main dilemmas arise: the difficulty of controlling her diet, and the threat this poses to her health. The difficulty of accepting individual timetables. It needs to be possible to create individual timetables for all the people who live in the home.

Identification of the issues of greatest conflict

Perspective of the elderly person or the family	Who has the authority?	Perspective of inter-disciplinary team
What conflicts regarding perspectives and/or values exist?	THE SITUATION / THE DILEMMA	What ethical principles arise?
Perspective of the auxiliary geriatric staff	What power relations affect the decision?	Perspective of the organisation and management team

1. Conflict of perspectives:
   Differences are beginning to emerge between the perspective of the elderly person and her son on the one hand, and that of the inter-disciplinary team, and especially of the doctor and the auxiliary geriatric staff. Although the son recognizes the suitability of the resource for the type of help his parents need, he asks that they be allowed to maintain habits which had been deemed unhealthy when they still lived in their own

home. By contrast, the care team's assessment of the health situation identifies the need for close supervision of diet.

2. Power relationship:
   Doctor – care managers – geriatric auxiliary staff.
   The possibility that residents of the home might choose their timetables according to their individual needs is seen as a threat which could make the life of the community impossible. Staff with care responsibilities oppose this possibility and obstruct its implementation.
3. Ethical principles: self-determination vs. duty and virtue.

Proposed Solutions

Negotiate that one of the meals should be taken in the dining room with everyone else.

Accept the possibility of individual timetables, but maintaining part of the rhythm of the shared life of the whole establishment.

Supervision of food in the room: products and ways of conserving it. Only products which do not require refrigeration. Accept the possibility of keeping food, but with the supervision of staff with regard to the type of product and how it is stored.

Final Comment

The training of care teams in taking ethical decisions is a process which requires time and determination: time to construct a methodology which allows us to improve analysis of situations, and determination to be educated in bioethical concepts. The analysis must encompass the perspectives of all those involved. Each perspective is a partial vision of the situation and, therefore, the methodology is a key element in constructing a global vision. The lack of these elements increases the risk of taking decisions which are overly subjective and lack coherence with the values the organization wishes to promote.

Reflections of a Man Approaching his Hundredth Year

Moisès Broggi Vallès

In the first place, I would like to say how delighted I am to be taking part in this symposium on a topic of such interest and relevance as the issue of how we deal with old age.

Everybody knows that the human body goes through a predetermined cycle of change which starts with birth and childhood and leads through youth and maturity to old age and death. In this view, old age is the final stage, a prelude to death, in which there is a noticeable decline in most vital functions; muscles weaken, senses become less keen, bones become fragile and painful, the nights become long and arduous, and the individual becomes increasingly sensitive to cold and heat and to all sorts of illnesses and external influences.

Not all of us go down this slope at the same speed, and the rate of descent depends, among other factors, on health, heredity, standard of living, chronic illnesses, the environment, stress, setbacks and many more. However, whatever his or her individual circumstances, from an economic viewpoint the elderly person becomes an unproductive being who needs the help of others, posing social problems which have been dealt with in different ways at different moments of history.

Since time immemorial, in stable, agrarian societies, the elderly, while very few in number, were respected and valued for their experience and for the wisdom of their advice at times of conflict. Several generations of one family lived in the same home, contributing to bringing up the young and helping with many daily tasks. A German legend reflects this situation well. It concerns a man and his wife who live in the country with their children and a grandfather. After a poor harvest, his son and his daughter-in-law decide to take the old man to the poorhouse. The next day, the man helps his father to prepare a bundle of belongings and the two men set out. After walking for a few hours they start to feel tired, and sit down to rest on a rock by the side of the road. The old man begins to cry and explains to his son how this reminds him of how, when he had been young, he had done the same thing with his father and how they had sat on the same rock. Upon hearing this, the son, whose conscience is far from easy, stands up and tells his father they are going home.

This story has a great moral force which indicates the son's state of mind; he is aware that he is acting wrongly, violating the deeply rooted duties which derive from good customs. The words of the father reveal the value of an ancient tradition which states that the old man must end his days among his family if he wishes his own children to follow this example.

In modern, industrial societies, this is increasingly difficult, as people concentrate in large cities where they live in small apartments, which they must then leave in order to go to work, leaving old people alone and marginalised. As a result, there is a growing need for old people's homes to take them in, separate from the family nucleus where they had passed their lives. In this regard, we should recognise the great effort our society is making.

While all of this is true, old age, like life itself, cannot be viewed from a strictly material point of view. Scientists tell us that life neither starts nor ends, but is a continuity of changing forms, one of which is old age, which is the prelude to the end of our physical body. Life is not a static system but a system which, maintaining similar forms, undergoes a process of constant renewal of the material which constitutes it. This is what physicists call a stationary system, similar to what happens with a flame, whose incandescent particles change continuously. The same could be said of our body in which, over the years, all the material of which it is constituted changes, even while maintaining a recognisable form and structure. In other words, from a material point of view I am not the same as I was only a decade ago, if it were not for my memories, desires and feelings and the whole spiritual aspect which forms the true basis of our personality. It is said that Buddha, before dying, pronounced the following words: «I know that my end is approaching, that life is constant change, and that nobody can avoid bodily disintegration. At this time, I can feel how my body is crumbing, exactly like an old used carriage, having served me during my arduous journey through this life,» and ended by saying, «Do not lament in vain. Think that in this world nothing is permanent, and in the emptiness of human life.»

Indeed, the material world does not explain every phenomenon of life, which is a continuity of changing forms, one of which is old age, a prelude to the death and disintegration of our body. And we must recognise that every stage

is full of pain and suffering, but also of pleasure. Old age, for example, despite its misfortunes, also has its own delights, and we must know how to make the most of them. The clear limitations of old age, both in terms of mobility and the senses, which impede contact and relations with the external world, contribute by contrast to consideration of the meaning of life, and to facilitating our understanding of our inner life.

The old person's vision of the world is very different from that of the young. A young man has his life in front of him, with its uncertainties and threats, and he strives to the utmost to find a security which is difficult to achieve. By contrast, the old man, as the years go by, sees how his personal future shrinks, knows that he does not have a future, that the human adventure is coming to an end, and this is when the past acquires greater prominence and offers him lessons. He then relives a world full of memories inhabited by people with whom he has lived and who have lighted up his life but who no longer exist. As a result he understands that nothing in this world is permanent, that everything is ephemeral and passes like a breath, and even everything which had seemed most solid and consistent also ends up disappearing. He also remembers how those pleasures and desires which he had so eagerly pursued in search of happiness were nothing more than false illusions which often concealed disappointment. It is also easy for him to understand that what dominates life is not happiness and pleasure, but anxiety, misfortune, suffering and often a great void which many vainly seek to fill with frantic activity or the abundance of material goods.

In other words, the more one thinks and reflects upon one's past life, the easier it is for the elderly person to renounce the material world and to enter a state of tranquil serenity which enables him to accept the natural laws to which we are all subject.

This attitude of the elderly person towards death is an interesting one, as the closer he gets to it, the less he fears it. The process of decline makes him understand, each time with greater lucidity, that death approaches and must be accepted as something which is both natural and perfectly normal. He accepts that the greatest satisfactions of our lives derive from our relationships with those we have loved and who have loved us, from the teachers who

have taught us and from all those who have been by our sides and have accompanied us or still accompany us along the path of our existence. We believe that this spiritual vision is the highest stage which man can achieve with his thought, which merges with the world of the mystical, and which one can reach at the end of one's life, however long this may be.

I will end by recalling an eastern saying: «When you were born, everyone laughed with happiness while you cried bitterly. Try to live in such a way that, while you die, everyone cries with sorrow and you may smile placidly.»

Barcelona, 15 May 2007

Some reflections on autonomy and longevity

Mercè Pérez-Salanova

One of the routes of investigation suggested by the speakers regards the conditions which influence how autonomy is configured. This is the route I propose to consider, analysing two aspects: the contextual and the interpersonal. In the first of these dimensions, my analysis focuses on the regulatory environment, together with the attendant organisational aspects. This involves both the analysis of regulatory frameworks in order to understand one of the key factors which influence the exercise of autonomy (Collopy, 1995) and also the innovation represented by the passing of the law on the Promotion of Personal Autonomy and Care for people in a situation of dependency.

My analysis of the interpersonal dimension focuses on the conceptions of those who help and care for elderly people who suffer from functional limitations. I am particularly interested in how these concepts influence the organisational function which these conceptions exercise over what we do as people; the study of these in relation to the care for the elderly offers a useful route to understanding what is happening and to identify potential ways of improving this (Sánchez-Candamio, 2004).

The regulatory framework: the Law on The Promotion of Personal Autonomy and Care for People in a Situation of Dependency (Act 39/06)

Act 39/06, approved by the Spanish Parliament in December 2006, establishes the right of people to receive provisions and services, which are graduated according to the degree of dependency and on the basis of a scale designed for this purpose. Before the law was passed, the White Paper on Care for People in a Situation of Dependency in Spain (2005) was published, and the index for this document is indicative of the range of issues it addresses[1]. It should be

1. Demographic basis: Estimation, characteristics and profiles of people in a situation of dependency. 2. Legal framework for the protection of dependency. 3. Long-term care provided by the family. Informal support. 4. Resources for caring for people aged below 65 in a situation

noted that while this law is not targeted exclusively at the elderly, this group constitutes the majority of those affected, both according to statistical estimates and from evidence regarding the application of the law[2].

The approval of Act 39/06 established a new set of regulatory coordinates and it is therefore interesting to consider how they record autonomy, something which is expressed through the participation of individuals. Participation is formulated as one of the key principles of the law: that is, as a guiding principle of the legislation. Given this prominence, it is worth considering not just those articles of the legislation which make explicit reference to participation, but also those elements which can be seen as being linked to the participation of people as subjects both at the individual and collective level. In this sense, the explicit mentions of participation are found in the formulation of policies, the exercise of decisions and, at the applied level, in the Individual Care Programme, together with the mention of basic principles such as respect for dignity or the right to receive information.

I think it is also worth analysing the Act from a «participative» perspective which focuses on those issues which, while the link is not made either explicitly or implicitly, may either promote or hinder participation. An analysis of this type requires us to take into account not just the wording of the legislation but also its policy features in comparison with other welfare policies. Using this approach, we can identify and evaluate four key aspects of the Act (Serra 2007):

---

of dependency. 5. Social resources for elderly people in a situation of dependency. 6. The health system and care for people in a situation of dependency. 7. Health coordination. 8. Financial budgets and resources allocated to funding dependency. 9. Assessing dependency: criteria and techniques for assessment and classification. 10. Generating employment and economic and social returns deriving from the implementation of the National Dependency System. 11. Analysis of practices and protection of people in a situation of dependency in some European Union and OECD states. 12. Considerations regarding the protection of people in a situation of dependency.

2. According to the data provided by the Statistics Service of the SAAD-IMSERSO regarding applicants to February 2009, 79.9% of these were aged 65 or older.

1) Public leadership of the social services sector in the design, implementation and management of the Dependency Care System.

2) Modification of the public welfare policy criteria which regulate the other two welfare systems based on the provision of services: health and education.

3) The organisational model, characterised by an inter-sectoral and inter-territorial approach (all levels of the administration, health and social services, public and private sectors, profit-making and not-for-profit).

4) The choice of a highly structured model based on public-private cooperation both with regard to meeting demand, that is, a mixed market, and with regard to the strategy of delivering publicly owned services by obtaining them from external suppliers.

Serra argues that the new law has been designed to avoid imbalances between the legitimate demand for and the real supply of services, and to ensure fairness. However, the legislation incorporates many elements of complexity (legal, technical, organisational and economic) which existing organisational and management structures are not necessarily capable of handling.

This assessment identifies an issue which is of relevance to our analysis: weakness at the level of organisation and management. This is where the Act actually takes form for citizens, and its configuration –both substantive and operational– therefore largely depends on participation being an integral part of the application of the Act.

We will narrow down the field to which we apply our analysis of participation by focusing on home-based care, given that most elderly people with functional limitations either live in their own home or with relatives. In this regard, we can identify three key issues on the agendas of local governments when it comes to implementing the System for Autonomy and Care in Dependency (SAAD): the service provision model; how the production of services is managed; and the organisational adaptation of municipal structures.

With regard to the service provision model, we need to highlight issues such as the identification of the entry point to the system, the supply of services, and recipients.

With regard to the management of the production of services, it is important to consider a wide range of issues. These include public–private partnership, the market situation involving both large and small companies, the employment market (in terms of availability of resources, training and regularisation), the relationship between the health market and the social services market, the contracting process, reference prices and management control, cooperation with the not-for-profit sector and voluntary organisations, and with families.

With regard to developing the organisational capacity of municipal structures, we should take into account the adaptation of primary social care, the management of public-private partnerships, and the management of relationships with the health and social care sector, in those regions where this is in operation.

These issues are closely related to the development of participation by elderly people and their carers within the family. In some instances, the relationship is easy to identify, as is the case with identification of the entry point to the system, the adaptation of primary social care, or cooperation with voluntary organisations and families. This is because these issues relate to situations where members of the public interact with professionals, as this is the channel through which people interact with the system (ignoring for the moment the possibility of virtual contact).

In other cases, identifying the connection between these aspects and the promotion of participation is less straightforward. This may be the case with regard to the market or the contracting process. However, these issues may have a secondary influence on the development of participation.

To clarify this function, we can briefly consider two issues: the market situation and the contracting processes. The market situation offers a scenario in which two types of actor predominate: large companies, and small and

micro-enterprises (including the self-employed). Each of these actors operates on the basis of a more or less detailed model of care, either explicit or implicit, and this may or may not include the question of participation. If there is an explicit model, then participation may be restricted to a set of statements or may be built into the organisation. The conditions mentioned here are just some of those which influence the development of participation, but they make it possible to identify how the market situation, even if it is not the «space» where participation occurs, may determine this.

A similar thing happens in contracting processes. The greater or lesser fluidity of these processes and how confusing or straightforward they are may help to ensure that service provision is speedier and more adaptable, or on the contrary these processes may become the axis around which the organisation revolves. These two approaches lead to lesser or greater levels of bureaucratisation and, as we are all aware, bureaucratisation is the enemy of participation. Again it is clear that, although contracting processes are not the «space» of participation, they determine this.

By identifying the influence of these aspects –both those which directly relate to participation and those which apparently have a more distant relationship– the result of a «participative reading» alerts us to the complexity of promoting participation, that is, to expressing autonomy, and stresses the importance of which approach we take, if such participation is our aim. In complex situations, the tendency is often to simplify the issues in order to make them easier to address, and to segment the issues under discussion with the argument that including such connections makes it difficult to operate. And we could also add a third approach: pushing these «complex issues» into the background and prioritising others. Any of these three approaches would impede the promotion of participation, although it is the last of them which could initially present most obstacles to ensuring that the principles of recognition of autonomy are translated into action, that is to say, that they are implemented.

It is worth considering that there are a number of factors in support of this approach, of which I will highlight three. The first of these is the pressing need for services, a situation which opens up the possibility of claiming that

the urgent nature of the situation imposes other priorities. According to this argument, the dedication required to facilitate and encourage the expression of autonomy among elderly people has no value. The second factor concerns the widely extended tendency to consider elderly people with functional limitations as «non-autonomous» individuals, confusing the need to receive help from others with the disappearance of the capacity for self-governance, or failing to differentiate between the two dimensions of autonomy: that which regards the taking of decisions, and that which regards the implementation of these decisions. As a consequence, the promotion of autonomy is marginalised and pushed into a «shadow area». And finally, the third factor concerns the view held by many elderly people, in particular those of advanced age, that they constitute a burden. Feeling oneself to be a burden causes unease, sadness and loss of spirit when facing situations which require energy and commitment, such as explaining and defending how one wishes to be helped; only those who channel their energies in this direction will promote the recognition of autonomy as a value. Given all of this, it is no trivial matter that the term «the Dependency Act» is often used in day-to-day references to Act 39/06.

Relationships: Autonomy at a Crossroads

If what I have said above with regard to the legal framework has addressed the nature of the context (primarily in general terms) in this section I propose considering the field of relationships.

As I already mentioned at the start, for elderly people who have functional limitations, the conditions under which they exercise their autonomy are configured in their daily life. They do so in a wide range of situations: ordinary, everyday moments which are far removed from «big decisions». It is at this level that relationships acquire their importance, and this importance is based both on what happens and on the meaning which is ascribed to what happens. It is therefore important to reflect upon the how autonomy is configured from the

perspective of relations between elderly people and those who intervene in their care in a variety of ways.

To explore this further, I shall look at part of the results of the AUTOGO[3] research project, which aimed to explore the conceptions of the participation of elderly people with limited functional autonomy who live at home, using a qualitative methodology based on interviews and discussion groups. The results I will use are those which correspond to the conceptions of: elderly people with functional autonomy, family carers (children and spouses), volunteers, professional carers, and professional managers of home care services.

The analysis of the discourse of the six discussion groups is presented below, showing firstly what are the key notions in each of the positions studied and secondly the overall trends which emerge.

The Key Notions: Concerns and Aspirations

The key notions reflect the central components in terms of the concerns and aspirations which the different positions studied associate with the exercise of autonomy by elderly people with functional limitations.

The first of the positions which we consider is that of elderly people with functional autonomy. It should be noted that in this group two different areas of concern and aspiration emerge, and this split corresponds to the different generational perspective of the informants. When these adopt the perspective of the intermediate generation –that is, as children– the concern revolves around *imposition* and aspiration revolves around *consensus*. When the perspective is that of the older generation –that is, as people likely to need help– concern is organised around *being discarded* and aspiration takes the form of the *desire to feel integrated*.

3. Proyecto AUTOGO – Desarrollando la participación de las personas mayores. Oportunidades y retos de la implantación de la Ley de promoción de la autonomía personal y atención a las personas en situación de dependencia en los servicios de atención domiciliaria. Refa. 65/06 Programa de Ciencias Sociales, Económicas y Jurídicas (Envejecimiento y Dependencia)-IMSERSO 2006.

The second position is that of daughters who assume the role of principal carer. Among these, concern focuses on *blackmail* and aspiration focuses on *recognising the care they provide*. It is worth highlighting the fact that the feeling of coercion is associated with conditions of a lack of cooperation from other family members and that the aspiration to recognition –from the person being cared for– is also directed, although to a lesser degree, at other members of the family.

The third position is that of people who intervene as volunteers. Among them, concern is formulated in terms of *silencing* and aspiration in terms of *accompanying and listening*. In this group, the subject both of concern and of aspiration are the elderly people with functional limitations.

The fourth position is that of the spouses who perform the role of principal carers. Among them, concern focuses on *the anxiety to care well* and aspiration is formulated in terms of *receiving support and guidance*. It can be seen, then, that these family carers include professional intervention in their aspirations, unlike the group consisting of daughters who provide care.

The fifth position is that of the professional carers. Among these informants, concerns focused around their *place as strangers* for the elderly person they are caring for, and their aspiration is to achieve a *relationship of trust*. In other words, there is a continuum between the concern and the aspiration, with the first defining the start of the relationship and the second being posited as the outcome to be achieved.

Finally, the sixth position is that of professional home care service managers. Among these, concern revolves around *insecurity* while aspiration concerns *guarantees*. In this group, as happens in that consisting of volunteers, the subject both of concern and of aspiration is the elderly person suffering from functional limitations.

As has been made clear, the different positions express different conceptions. While detailed analysis of the discourses which emerge in the different groups would allow us to further explore the components which constitute the different conceptions, these concerns and aspirations provide the principal axes around which care is organised. Both concerns and aspirations delin-

eate forms of relationship which may either promote or hinder the expression of autonomy.

Identifying Trends

In addition to understanding the key notions which came out of each discussion group, it is interesting to consider whether there are any trends which are shared between the different positions. To study this, we asked two questions: firstly, what is the attitude regarding autonomy? And secondly, what importance is attributed to how these difficulties are experienced by elderly people with functional limitations?

With regard to both issues, we explored the influence of the type of link –family or non-family– the generational position, and the life stage. The main focus was on recognition of the right to self-determination in the discussion groups consisting of volunteers, professional carers and professional managers: that is, among those people who do not have family ties. This is also the case for the group of elderly people when they adopt the perspective of the older generation, of people who may need help. And it is also the attitude, to a lesser degree, of spouses.

In contrast with the recognition of autonomy of these groups, the attitude focused on self-protection in two discussion groups: that consisting of daughters caring for a parent, and that consisting of elderly people when they adopt the perspective of their daughters. In both cases, the carer and the recipient of care form part of the same family.

Recognition of elderly people's experience of the difficulties entailed by the loss of functional capacities follows a different pattern. The group consisting of daughters caring for a parent scarcely mentions them, while all the other groups do.

It is clear, then, that the type of link influences the response to both questions, and this influence reflects both the generational position and the life stage, where there is a family tie.

The trend which emerges with regard to the influence of family ties expresses the tension felt by family carers, the doubts they feel, and the dilemmas in which they are often trapped. The differences according to whether the carer is a spouse or a daughter are indicative not only of the nature of the tie, whether between spouses or between parents and children, but also the difference between generations with regard to feelings of filial duty. This difference also depends upon the stage of life of the carer, and daughters caring for a parent may also have to deal with the challenge of being good daughters, good mothers and good spouses, while also holding down a job.

In this regard, it is interesting to consider the results of research carried out in Canada (Lavoie et al, 2003) into the interaction between services and family carers in which an empowerment perspective was applied. Among those carers for whom caring constituted a central part of their identity and among those who were in later stages of life, interaction with services promoted greater control over the situation, providing support or legitimising their use of services. By contrast, where family carers were trying to reconcile their care role with other duties, either because they were trying to combine a range of responsibilities or because they sought to limit their involvement in help and caring, they came up against the inadequacy and rigidity of these services and the distrust of many of the professionals they dealt with, and this increased their feelings of impotency with regard to the situation. The results which emerge from the contextual dimension of empowerment shed light on the interaction between factors which are external to carers and those which are intrinsic to them, such as their life path and identity.

Likewise, with regard to the attitudes of carers to the autonomy of the person they are caring for, it is interesting to note the consideration of different models in the relationship between health professional and patient (Broggi, 2004). His analysis of the different models –paternalistic, contractual, interpretative/personalised and deliberative– allows us to appreciate distinctions between those who recognise autonomy. While it is true that the clinical relationship has specific features which differentiate it from the relationship between an elderly person living at home and his or her carers, the two relationships also share many aspects. As a result, characteristics such as the docility or infanti-

lisation of the paternalistic model are expressed with greater intensity between those who share family ties while the elements of the contractual or deliberative model can be seen, although less consistently, among people who act in a professional function.

The conditions reflected by this data make very clear the wide range of obstacles which lie in the path of the exercise of autonomy by elderly people suffering from functional limitations. At the same time, analysis of them enables us to identify some ways of reducing these difficulties and, in this way, to promote autonomy. I shall therefore conclude by presenting some of these.

Conclusion: Building Bridges Towards Autonomy

Let us start by considering the approach taken. This must start by recognising the complexity of care situations, as we have explained, and taking into account the requirements of implementing Act 39/06. A further complicating factor is the range of views of the groups of individuals participating in the care process. Only by accepting this complexity can we hope to promote a participatory approach in the practical implementation of the law, and favour ways of doing things which are not limited to the management of services but which incorporate tension and conflict. Indeed, accepting complexity means recognising tension and discomfort, and appreciating the structure and dynamic of interdependence. Elderly people who need care sometimes reject the help of others because they feel it to be invasive, something which changes their lives by bursting into their private space. This situation, which is far from uncommon, requires that carers –whatever their role– are able not just to describe and explain what is happening but to understand it. Conflict, tension and discomfort are also expressed in the relationships between relatives who care and the elderly people who need care. In such cases, simply providing a service but ignoring the conflict prevents this resource from making an effective contribution to care. Both situations need to be understood and

require the specific support necessary to ensure that the help provided constitutes a viable basis for care. Only in this way is it possible to build bridges towards autonomy in complex situations.

Secondly, we believe it is important to consider information and reception. We are referring to the different sequences, settings and formats by means of which people hear, read or see, and in which they are able to ask in order to understand what their rights are. These settings may vary greatly. Information should guide and be straightforward, it should reflect and transmit the value of autonomy, as a failure to do so can only lead to autonomy being neglected.

Reception has a range of meanings both for elderly people and for the relatives who care for them. Some see it as the place they didn't want to reach, while for others it means finally arriving at a destination which dispels their sense of abandonment. Help cannot be associated, or at least not exclusively, with predetermined settings or situations. The person responsible for reception, whether in the form of orientation or evaluation, has the opportunity to build bridges towards autonomy. As a result, the training of these individuals must not only provide them with the necessary techniques and knowledge, but should also help them to develop their interpersonal skills. Technical knowledge alone does not provide a sufficient basis for generating trust, which is essential for high quality care.

Reception is not limited to the initial moment in the process of searching for and providing help. Reception continues afterwards, and acquires particular relevance when defining the Individual Care Programme, and this may be another opportunity to build bridges towards autonomy. The Individual Care Programme can take two forms: as a framework for allocating services or as a framework within which participants jointly define a care project. Both versions are compatible with the stipulations of the Act, so long as there is agreement. However, they are at opposite poles if we see the Programme as an opportunity for building bridges towards autonomy. In addition to the interpersonal skills, noted above, we can add another issue: the adoption of an empowering perspective.

Finally, in third place we believe it is important to stress one aspect which may go unnoticed: the absence of a culture of rights. When this shortcoming is combined with the predominant conception, which reduces autonomy to functional autonomy, the effect is doubly negative: the individual may be reduced to his limitations, being seen in this way by others and seeing himself in this way. If we are to ensure that these elderly people feel themselves to be subjects with the right to self-determination, we cannot ignore their hopes and desires; this recognition means valuing their experiences of care. In other words, the way in which these people assess care, the things which they identify as making their lives better or worse, must become the basis for establishing criteria to improve the design and implementation of services. Only in this way is it possible to ensure that the framework and the living conditions proposed are suitable and acceptable, that they should be experienced with dignity rather than being received with resignation. In this regard, we can identify two lines of action: the first of these concerns the far-reaching incorporation of a bioethical perspective, and the second the drawing up of a Bill of Rights, the composition, dissemination and monitoring of which should take the involvement of elderly people with functional limitations as an indicator of good practice. Both lines offer ways of speaking about, thinking about and practising interdependencies in which autonomy is not ignored.

References

Broggi, M.A. (2003) «Gestión de valores 'ocultos' en la relación clínica». *Med Clin (Barc)*, 121:294-296.

Collopy B. J. (1995) «Safe and unsound». *Contemporary Long term Care,*18 (8):44-8.

Imserso (2005) *Libro Blanco sobre la atención a las personas en situación de dependencia en España*. Ministerio de Trabajo y Asuntos Sociales. Secretaría de Estado de Servicios Sociales, Familias y Discapacidad.

Lavoie J.P., Lessard D., Barylak L., Côté D. (2003) «Quand les services facilitent ou nuisent au pouvoir des aides familiares». *Canadian Journal on Aging/La Revue canadienne du vieillissement* 22(4) :381-394.

Sánchez Candamio, M. (2004) Estudio sobre la complementariedad entre la atención formal y informal a las personas mayores desde la perspectiva de sus agentes principales. Unpublished report. Barcelona Local Authority.

Serra, A. (2007) «L'atenció a la dependencia: un nou model de gestió de política pública de benestar social». En Col·legi d'Economistes de Catalunya *El quart pilar de l'estat del benestar: l'atenció a la dependencia*. Revista Econòmica de Catalunya, 56: 106-116.

List of Invited Specialists

- Mercè Pérez Salanova, psychologist and lecturer at the Autonomous University of Barcelona. Institute for Ageing.
- Bernadette Puijalon, anthropologist at the Paris XII University.
- Josep Vila, graduate in Psychology from the Autonomous University of Barcelona.
- Moisès Broggi, doctor and president of the Letamendi-Forns Foundation.

Publications

Monographs:

16. *Autonomy and dependency in old age*
15. *Informed consent and cultural diversity*
14. *The issue of patient competence*
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. *El uso racional de los medicamentos. Aspectos éticos* (The rational use of medication: ethical aspects)
7. *La gestión de los errores médicos* (The management of medical errors)
6. *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 of the Foundation:

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

Etical Questions:

1. *¿Qué hacer con los agresores sexuales reincidentes?* (How to deal with repeat sexual offenders?)

For more information, visit: www.fundaciongrifols.org

FUNDACIÓ

VÍCTOR

GRÍFOLS

i LUCAS