NOTES

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"It has been calculated that in Spain there are about 400.000 people who suffer from schizophrenia or could suffer from it at some time in their life. ¡¡¡400.000!!! You're bound to know one of these people even though you haven't realised it. Whether we know it or not, we all know someone who suffers from it. What usually happens is that we turn our back on them and talk about them in private or in a low voice, due to fear of the unknown. If these figures seem high, pay attention: anyone of us could be affected, in one form or another, by schizophrenia: maybe because it affects you yourself, or a member of your family, a friend, a neighbour, a classmate or workmate...".

Carmen Carrascosa. ¿What is schizophrenia? *A story about Luis*. Project Chamberlin. Complete text at **www.proyectochamberlin.org**

Notes for page 15

"Recovery with respect to mental illnesses has been defined as «a deep and personal process of change of attitude, feelings, perceptions, beliefs, work carried out and vital aims». Besides, recovery has been considered as «the development of a new meaning and new aims in personal life, beyond the impact of mental illness". This definition includes or implies some of the more usual elements of many other definitions which have been proposed over the last 15 years: the importance of the renewal of hope and the meaning of things; the overcoming of stigma and other sources of traumatic situations associated with serious mental illnesses, and the assuming of control of your own life".

Marianne Farkas. The current consideration of recovery: what it is and what it means for support services. World Psychiatry (Spanish Edition), September, 2007.

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"While human beings are the victims of random misfortune, rather than premeditated or natural, with equal opportunities we are not obliged to accept it without reply. We can find means to counteract cruelty and apparent indifference. Nature lacks a plan for human prosperity, but as natural human beings we are permitted to design such a plan. A combative attitude seems to contain the promise that we will never feel alone while our worry is the welfare of others".

Antonio Damasio. En Busca de Spinoza. Neurobiología de la emoción y los sentimientos. Crítica, 2005.

Notes for page 17

1. "Psychosocial rehabilitation is today considered as an unavoidable, basic service to confront, detain and reverse that venomous evolution towards personal alienation and social destructuralisation. While psychosocial rehabilitation is still an individualised process in which various structured and systemised psychological and social practices are combined, it transcends this pragmatic limit to become a philosophy, a way to understand these severe bio-psychosocial problems".

Juan Fernández. Las intervenciones en rehabilitación tienen limitada su eficacia. La Gaceta del CRL. Junio, 2004.

2. "Someone who is ill is not a different being, but a person just like everyone else capable of loving, suffering, being grateful, and like everyone, needs affection".

Leader of the first issue of the magazine Nanacinder. Psychiatric Colony of Bárbula. Valencia, Venezuela, 1952.

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"Training in social abilities is not rehabilitation; it may be a miniscule part of it. Decapitated rehabilitation is a deceptive point which knows of the unworkability of its own discourse. If it poorly enriches what is left, it is well aware of its inefficiency in developing the potential of a man. Weaving carpets, making tortillas, reading the newspaper or saying good morning don't open up opportunities in the world of work. Work needs to have a meaning; if this is not the case, once help has been exhausted, solitude, helplessness and new dependence will return. It is not surprising that current rehabilitating procedures are poorly accepted. Without integration in a normalised social texture, the huge step taken by neuroleptics will be of no benefit. The revolving door will, in the end revolve again. Today I visited a centre of "socio-work rehabilitation". As always, in the middle of the leaves piled up in the path, there is space to see flowers grow".

Antonio Colodrón. Rehabilitación Integradora. La Gaceta del CRL, Nº 13. July, 2001.

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"I personally have no doubt that people with TMG form a group that is truly disadvantaged. The stigma means that, on one hand those affected and their relatives don't get to collaborate, and on the other hand their voices are not raised, as occurs with other groups. Silence means that at times these people are forgotten when it comes to handing out resources. But I don't believe that the AAPP discriminate against us, but simply that they attend those who most demand it. Social prejudice can be combated with the real demonstration that not only can they live and work like other people and that they need the same support, but also by showing that they have been doing this for a long time and that more and more people achieve it".

Francisco Sardina. President of the Manantial Foundation. Text for *A story about Luis*. Project Chamberlin. Complete text at **www.proyectochamberlin.org**

Notes for page 20

1. "Support services centred on the person or on the complete human experience and not on «cases», those focussed on participation and not on obedience, on choice not coercion, on the promise of hope and not despair. These all permit us to embrace the hope of achieving an objective above survival or maintenance of the current state of affairs. These services encourage the recovery or restarting of a fully significant life for those people who suffer from serious mental illnesses".

Marianne Farkas. The current consideration of recovery: what it is and what it means for support services. World Psychiatry (Spanish Edition). September, 2007.

2. "Patients who accept a diagnosis of mental illness feel an internal pressure to a stereotype of incapacity or uselessness".

Warner, R., Taylor, D., Powers, M. et al. Acceptance of the mental illness label by psychotic patients. Am J. Orthopsychiatry, 1989.

Notes for page 21

"The need to value perceptions and experiences of each person is often stressed to members of self-help groups. Whether these groups are formal or interact informally among their members, what is key to the experience of self-help are consoling words and empathy, which usually lead to spectacular results. In these groups it is inadvisable to use the diagnostic terminology, although many people with years of experience in the mental health system have learnt to use labels to describe their behaviour and the behaviour of others. Instead of this terminology, we encourage members to use terminology of common sense, for example, "Today I feel bad" in place of "I'm having a crisis". We try to get members to see their thoughts, feelings and actions, and those of their companions as normal reactions to the tensions of real life and not mysterious "symptoms" over which they have no control at all".

Judi Chamberlin. Services aimed at users. Models of Madness. Herder, 2006.

Notes for page 22

1. "Fighting against the difficulties supposed by stigma requires multiple measures, articulated and sustained over time, directed towards a change in attitudes and their reinforcing factors such as modifying the barriers that this creates. Also helping those affected to manage these effects. This ranges from occasional protest at work with key social agents (educators, media experts and in the case of employment, businessmen and trade unions) to the more "visually impressive" than efficient "grand campaigns" in the media.

In general the fight against this complex social barrier does not only fundamentally require information, but above all social interaction with people with mental disorders that carry out normal social roles, especially work. The importance of this field of activity is not only for specific people who get a job but also for the whole group itself".

Marcelino López. Fundación Andaluza para la Integration Social del Enfermo Mental

(Andalusian Foundation for Social Integration of those with mental illness). (FAISEM). Director of Programmes, Evaluation and Investigation. Text for *A story about Luis*. Project Chamberlin. Complete text at **www.proyectochamberlin.org**

2. "In these moments INICO has built up a wide group of professionals, teachers and technicians, being one of the clearest references in investigation, development of projects and specialised formation for incapacity. (...) Supported Work is aimed at all groups without exception, including those people at risk of exclusion for different reasons of disability. People with mental illness show a lower level of integration at work than other groups because of the social stigma derived from their incapacity".

Miguel Ángel Verdugo. Director of INICO, University Institute of Integration in the Community. University of Salamanca. Text for *A story about Luis*. Project Chamberlin. Complete text at **www.proyectochamberlin.org**

Notes for page 23

1. "The failure of intelligence appears when someone is determined to deny the evidence, when nothing can make him back down, when a belief becomes immune to criticism or the facts which contradict it, when nothing is learnt from the experience, when it becomes an enclosed command. Psychiatrists know that many pathologies are characterised by these erroneous and incontrovertible assurances. Hallucinations are a clear case. The patient hears what they hear and nothing can convince that the experience did not really take place. In an environment of reality there are similar behavioural acts, which are clearly failures. Prejudice, as Allport explained, is "to be absolutely sure of something that you don't know". It is characterised by selecting information in such a way that the subject only perceives those facts which corroborate their prejudice".

José Antonio Marina. La Inteligencia fracasada, Teoría y práctica de la estupidez. Anagrama, 2004.

2. "Madness does not exist. However, it is the origin of ignorance and prejudice towards some of the mentally ill that has nothing to do with them".

Galilea, V., Colis, J. Enfermos mentales crónicos y su integración. El País. October, 1999.

3. "The value of language as a form of discrimination is unquestionable, (...) and so in our current society, starting with the names attributed to certain immigrants, women, homosexuals, the disadvantaged, etc., it is easy to promote attitudes and behaviour of rejection, marginalisation and, in a word, of stigmatization".

Julián Espinosa. Estigma, enfermedad mental y medios de comunicación. Boletín de la Asociación Madrileña de Rehabilitación Psicosocial. N° 13, 2001.

4. "What exactly is treating people as people, that is to say, humanely? It is trying to put yourself in their place. Recognising someone as like you implies above all the possibility of understanding them from inside, of adopting for one moment their own point of view. It is something that I can only do in a fictional or doubtful way if I try it with a bat or a geranium, however

this is not the case with beings capable of managing symbols just like me (...). If we don't admit that something fundamentally equal exists between us (the possibility to be for someone else what that person is for me) we couldn't even share a single word with them. Where there is a crossover, there is also recognition that in a certain way we belong to the person in front of us and they belong to us... Even though I am young and the other old, although I am a man and the other a woman, although I am white and the other black, although I am stupid and the other smart, although I am healthy and the other ill, although I am rich and the other poor".

Fernando Savater. Ética para Amador. Ariel, 2004.

Notes for page 24

1. "Psychology, but also Medicine, in general, have until now focussed on reducing discomfort, controlling symptoms, or alleviating illnesses. This is necessary, but is not sufficient to be in good psychological, physical or even social health. One of the crucial contributions of rehabilitation is that, since its beginnings, and we can go back even as far as the XIX century, it has been centred on the attempt to recover integral functioning in patients. In this sense it can be considered to have opened unsuspected paths and horizons. The so-called Positive psychology fairy emphasises the necessity to focus on that which contributes to the welfare and integral health of the citizens, obviously without forgetting about the relief of pain and suffering. The interest of Positive psychology in capacities, strengths, and welfare, converge perfectly on the horizon of psychosocial rehabilitation. On the road, we will have to discover how to identify and strengthen those capacities that are conserved, how to improve institutions so they are efficient generative tools of health and welfare (not only efficient at reducing misfortune) and in bringing about paths that permit people's growth. Clearly there are points of convergence between this model of capacities and that which has traditionally been the underlying epistemology of rehabilitation. I believe there can be meeting paths of great mutual benefit".

Carmelo Vázquez. Professor of Psychopathology. Faculty de Psychology. UCM. Text for *Astory about Luis*. Complete text at **www.proyectochamberlin.org**

2. "Despite periodical educative campaigns, prejudices continue to exist; this is reflected in the conflicts that arise around residential accommodation for these people, in an unfavourable social acceptance and in negative employment policies".

Ruffner, (1986). How psychiatric Disability Expresses Itself as a barrier to Employment. Psychosocial Rehabilitation Journal. Vol. 17. N° 3. January, 1994.

Notes for page 25

1. "Psychiatric rehabilitation is focussed more on treatment of the consequences the illness than of the illness *perse*".

Marianne Farkas. Avances en rehabilitación psiquiátrica: una perspectiva norteamericana. En J. A. Aldaz, C. Vázquez: Esquizofrenia: Fundamentos psicológicos y psiquiátricos de la rehabilitación. Siglo XXI. Madrid, 1996.

2. "Psychiatric rehabilitation is in no way any treatment for people with schizophrenia;

there is nothing rehabilitating or integrating, for example, in the repeated production of useless objects".

Rotelli, F. (1995) Tiempo de rehabilitación. Boletín de la Asociación Madrileña de Rehabilitación, N° 4. Madrid.

3. "The role of patient turns the individual into a *being* without time, static, on the margins of the natural passing of events; it is therefore an incapacitating, marginalising role, *a role that looks in on itself*. The normalised role permits the individual to join real time and by doing that (re)-know themselves, (re)-make themselves, (re)-habilitate themselves; the normalised role is dynamic, integrating, insufficient in itself, *look at others and their surroundings*. Rehabilitation tries to bring about a shift of role in the subject: from the role of patient to the normalised role".

Galilea, V., Colis, J. Algunas razones en favor de la rehabilitación laboral de personas con enfermedad mental crónica. Rev. Trabajo Social Hoy. N° 28. Monográfico 1er semestre. August, 2000.

4. "It is considered that the implication of the patients themselves in the design and application of mental health services (e.g. planning, implementation and evaluation of programmes) is a critical component in the system of quality control of any mental health service, as is a key aspect in the development of the feeling of strengthening and of the increase of self esteem.

The active promotion of employment of people who suffer from serious mental illnesses as help and support staff, or as assistants to the professionals and administrators, is becoming an important element for the development of services orientated towards recovery. The slogan of the movement consumers and users «Nothing for us without us» summarises the expectations of implication and participation in a service orientated towards recovery".

Marianne Farkas. The current consideration of recovery: what it is and what it means for support services. World Psychiatry , 2007.

Notes for page 26

1. "In the treatment programmes for people with schizophrenic disorders, work, with its social network, plays a relevant role. That is to say, with those people of their surroundings (family, friends, workmates, companions from the centre of rehabilitation, etc.) with those who have established direct or indirect connections and relationships. To a certain extent, maintaining an existent social network or the creation of new social networks that carry out a function of support are some of the most important objectives of programmes of rehabilitation. Therefore centres of psychosocial rehabilitation and centres of work rehabilitation, besides their more specific tasks, contribute to boosting the social support network of their users".

Mª Fe Bravo. Redes sociales y evolución de la esquizofrenia. La Gaceta del CRL, Nº 13. July, 2001.

2. 2002 in Spain the highly interesting Project REdES was launched. It consisted of giving

work to people with chronic mental illness in the area of new technologies. Those employed concentrate on creating and maintaining web pages. They take their medication regularly, they have developed their capacity to live with others, they are well integrated in the world and they're brilliant, competitive and efficient in their work. They are, in the end, complete people, despite being ill".

Rosa Montero. No son locos (They're not crazy). El País Semanal, 2005.

Notes for page 27

1. "Carrying out work is, at the same time, a result and a determinant of the course of a mental disorder".

Liberman R.P. Rehabilitación Integral del enfermo mental crónico. Barcelona. Martínez Roca, 1993.

2. "I don't usually enjoy reading psychology manuals, in fact I try to avoid them because the majority of them are written in impenetrable prose lacking in all humanity. (...) My first contact with the psychiatric system goes back to 1961, when I was working in Sydney as an educational psychologist with special attention to youngsters with emotional disorders.(...) All the infant psychiatrists who I worked with there considered the patients and their families as people and not as simples cases with a specific diagnosis. No-one talked about genes or biochemical changes but of tensions and conflicts in their lives. I took for granted that this was habitual in psychiatry. Not until I started work in a clinic dependent on the Department of Psychiatry of The University of Sheffield did I understand that the psychiatrists in Sydney were really advanced in their way of thinking".

Dorothy Rowe. Foreword. Models of Madness. Herder, 2006.

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"The services should be able to support the aspirations of the people who wish to return to their university studies or finish high school studies, just as they should for those who wish to finish any level of study. The services should also facilitate the objectives of people who want to get married, have children and set up their own businesses, just like those who wish to live in some type of supervised residence and work in a more protected work environment. Hope does not mean using the promise of recovery as a new tool to stigmatize or devalue the individual. The impulse towards stigmatization of a person as « unmotivated» must not be substituted by the use of the label of «failure to recover» due to the person not having reached their recovery objectives yet. Just as has been demonstrated in studies of investigation, hope signifies that recovery can be a process requiring a long time, with numerous ups and down during its development".

Marianne Farkas. The current consideration of recovery: what it is and what it means for support services. World Psychiatry, 2007.

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"To know about emotion, feeling and how they work is important for the way we live. On a personal level, this is very true. Over the next two decades, maybe earlier, Neurobiology of emotion and feelings will permit biomedical science to develop effective treatments against pain and depression, on the basis of a general understanding of the way in which genes express themselves in determinate regions of the brain and the way in which these regions cooperate to make us experience emotions and feelings. The new treatments will be aimed at specific areas lacking in normal process instead of simply attacking the symptoms in a general way. Combined with psychological interventions, these new therapies will revolutionise mental health. Treatments now available to us will then seem so crude and archaic just as the way we view surgery without anaesthetic today".

Antonio Damasio. En Busca de Spinoza. Neurobiología de la emoción y los sentimientos. Crítica, 2005.