Community-based rehabilitation and the Clubhouse Model as means to recovery and mental health services reform.

Rehabilitación basada en la comunidad y el modelo Clubhouse como medio de recuperación y reforma de los servicios de salud mental.

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RESUMEN

Se examinan las tendencias de rehabilitación basada en la comunidad (CBR) y el modelo de rehabilitación psicosocial denominado *Clubhouse* (CH) como instrumentos de políticas de reforma de la Salud Mental (MH). El trabajo se basa en documentación del proyecto transnacional "Empoderamiento de adultos con enfermedad mental para aprendizaje e inclusión social en 2010-2012" además de otras fuentes. La colección de datos y subsecuentes análisis se prepararon en el contexto de cerca de 30 recomendaciones internacionales de políticas de salud mental desde los años 90 hasta el 2012. Los documentos fueron analizados y comparados con diferentes enfoques orientados a la recuperación, tales como el modelo CH, y con conceptos clave de la ciencia de Rehabilitación, vinculados con tendencias recientes de la rehabilitación psicosocial. Algunas de las más importantes recomendaciones intergubernamentales de políticas de salud mental son las Guías conjuntas de Trabajo de la Organización Mundial de la Salud (OMS) y UNESCO y varias asociaciones internacionales tales como la Asociación Mundial de Rehabilitación Psiquiátrica (WAPR) y el Marco Piramidal de la OMS para la óptima combinación de servicios de Salud Mental, complementados con el Plan Integral de Acción en Salud Mental 2013-2020 aprobado por la OMS este año. Todas estas fuentes incluyen el espectro total de trastornos mentales. Factores de combinación son los derechos humanos, basados en una comprensión más holística de las discapacidades en lugar de un enfoque meramente médico. Todas estas recomendaciones están orientadas a su utilización a nivel global.

PALABRAS CLAVE: Servicios basados en la comunidad, rehabilitación psicosocial, Modelo *Clubhouse*, políticas de salud mental.

SUMMARY

The article focuses on the trends of community-based rehabilitation (CBR) and the psychosocial Clubhouse rehabilitation model (CH) as tools for mental health (MH) policy reforms. It is based on documentation of the transnational project "Empowering Adults with Mental Illness for Learning and Social Inclusion in the years 2010-

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2012" and other sources. The collection of data and subsequent analysis were prepared in the context of about 30 international MH policy recommendations from the 1990s until 2012. The documents were analyzed and compared with different recovery-oriented approaches like the CH model and with the key concepts of rehabilitation science, linked with the recent trends of the psychosocial rehabilitation. Some of the most important intergovernmental MH policy recommendations are the United Nations (UN) Convention on Rights of People with Disabilities (CRPD, UN 2006), the joint CBR – Guidelines of the WHO (2010), ILO, UNESCO and several international associations as the WAPR (WAPR & WHO Consensus Statement 1996), as well as the WHO Pyramid Framework for the Optimal mix of MH services (WHO 2007), complemented with the WHO's Comprehensive MH Action Plan 2013-2020 approved in May 2013. All these sources include the spectrum of MH disorders. The combining factors are the human rights – based on a more holistic understanding of the disabilities instead of a merely medical approach. All the above recommendations are aimed at worldwide utilization.

KEY WORDS: Community-based services, psychosocial rehabilitation, clubhouse model, mental health policy.

Mental health reforms and community-based policy

The mental health (MH) reform movements started after World War II with a special focus on the new types of community-based services. Particularly during the 1950s the changes led to *a mental health policy with deinstitutionalization* first in North-America and later also in Western and Nordic Europe and Australia. The closing down of mental hospitals began then, as well as the development of compensatory community mental health services. During 1960s the first Day Hospitals, Home Treatment teams and outpatient nurses started their activities. In 1963 the first community mental health centres (CMHC) and acute psychiatric units in general hospitals were opened in the USA (1).

The mental health reform in Italy at the end of 1970s provided a clear illustration of this new community-based policy in Europe. In Trieste psychiatric hospitals were closed down and replaced by a wealth of community services (2,3). Changes took place slowly and at different speeds in different countries. In a global perspective, the mental health reform processes originated from a Westernised medical service model, omitting large parts of the traditional mental health services, still used by the majority of people with mental illnesses but seldom recognized by psychiatric research. A wider social paradigm started to emerge together with the human rights based approach since 1980s (4).

In parallel with the mental health reforms, the Clubhouse (CH) psychosocial rehabilitation model started to develop since 1948 in the Fountain House of New York City, as an initiative of former mental hospital patients. In the 1970s, Fountain House started to disseminate its experiences in the USA and Canada, and a few years later (in 1980) in Europe. Today the CH model that is based on Fountain House concept is used in all continents and has been replicated more than 400 times (5).

Caldas de Almeida and Killaspy (6) summarize the international trends and recommendations from a scientific point of view what is at stake is the replacement of the strict biomedical model by a *more holistic approach* which understands mental disorders as a result of the complex interactions of biological, psychological and social factors. These trends should be taken into account when the future mental health policies and psychosocial rehabilitation approaches and support services are developed and their performance and outcomes are evaluated.

Mental health policy recommendations and present situation

During the period 1990-2013 the intergovernmental organisations such as the United Nations with its specialist organisations WHO, ILO and UNESCO, and other international institutions launched at least 30 different policy guidelines, recommendations or reports to activate the mental health policy reforms (7). In 2006, the UN General Assembly defined the universal principles for disability policy in its new Convention on the Rights of Persons with Disabilities (CRPD) which also covers people with mental health conditions (8). By July 2013 around 155 countries in the world will have signed, and 133 of them have ratified the CRPD. The convention is legally binding in countries that have ratified it (9).

The similar holistic approach that is the core of the CRPD and which calls for the involvement of users and their families and for cooperation across

different sectors and professions is included also in the following key policy recommendations due to be materialized worldwide:

- UN resolution on the Principles for the protection of persons with mental illness and for the improvement of mental health care (10);
- UN Standard Rules on the equalization of opportunities for persons with Disabilities (11);
- Organization of services for mental health; a publication of the mental health policy and service guidance package (12,13);
- The Community-Based Rehabilitation Guidelines (14); and
- The Comprehensive Mental Health Action Plan 2013 - 2020 (15)

WHO published in 2003 the first version of an optimal mix of the mental health services. It was renamed in 2007 as the *WHO Pyramid Framework*. The key message of this document is that a major part of hospitalization practices can be replaced with a diversity of community-based services (13,16). The challenge is how to organize services by the most cost-effective and recovery-oriented way and follow the WHO Pyramid Framework. However, only few mental health service systems in the world are so far committed to realize the principles of the Pyramid Framework or to follow CBR-guidelines (17). The diversification of MH services in Italy is an example of how it has been possible to create and implement community-based MH policies by reforming MH legislation and practices throughout a couple of decades (3).

In the world the median mental hospital expenditures as percentage of all mental health budgets vary by WHO Regions from 36 % up to 77 %. Globally, 63% of psychiatric beds are located in mental hospitals, and 67% of mental health spending is related to these institutions. Worldwide spending on mental health is less than two US dollars per person, per year, and less than 25 cents in low income countries. Almost half of the world's population lives in a country where, on average, there is one psychiatrist or less to serve 200,000 people. Only 36% of people living in low income countries are covered by mental health legislation. In contrast, the corresponding rate for high income countries is 92%. Dedicated mental health legislation can help to legally reinforce the goals of policies and plans in line with international human rights and practice standards. Though resources remain concentrated in mental hospitals, a modest decrease in mental hospital beds was found from 2005 to 2011 at the global level and in almost every income group and Region (17).

In the coming years the above figures will present worldwide challenge to national and local policy-makers, urging them to intensify efforts for speeding up the implementation process of the MH policy recommendations and improve human rights standards for the benefit of people with mental disorders and their families. This development of this work should be based on the universal principles, human rights standards and community-based approaches which form the core of the mentioned guiding documents and recommendations.

The World Health Assembly will adopt in May 2013 the Comprehensive MH Action Plan 2013-2020. It covers the whole spectrum of mental disorders, and mental health as a state of well-being in which individuals realize their own abilities, can cope with the normal stresses of life, can work productively, and are able to contribute to the communities where they are living. In light of repeated violations and discrimination, the human rights perspective is essential in responding to the global burden of mental disorders. The overall goal is to promote mental well-being, prevent mental disorders, provide care, enhance recovery, promote human rights and reduce mortality and disability of persons with MH problems.

The action plan has four objectives: 1) effective leadership and governance for mental health, 2) comprehensive integrated and responsive MH and social services in community-based settings, 3) strategies for promotion and prevention, and 4) better information systems, evidence and research. The planned activities rely on six cross-cutting principles: universal health coverage, human rights, evidence-based practice, life-course approach, multisectoral approach like in CBR-guidelines, and empowering persons with MH problems. Each WHO Region has to adapt the action plan to the region-specific situations. WHO Member States are expected to coordinate national MH policy priorities with the objectives of the new worldwide action plan (18).

Common denominators of international policy recommendations

Notwithstanding that the analyzed policy recommendations have been approved during different decades, they include mainly similar universal

principles, goals and specific objectives for the MH policy reforms. The following list includes the major common denominators of the above international MH policy recommendations:

- Equal opportunities to exercise human rights and freedoms in all settings;
- Involving people with mental health problems in all decision-making and service development;
- Elimination of all kinds of discrimination and stigmatization;
- Full participation, reintegration and social inclusion in community on equal basis with others;
- Right to receive needs-based public services like social protection, housing, healthcare, professional training, and employment services;
- Coordination of community-based services with primary healthcare and general health services; and
- Self-determination, autonomy and independent living.

Behind the common denominators, certain key values, objectives and standards of the CRPD can be identified as the basis for all other policy recommendations published after year 2006 by the specialist UN agencies (19). For example, the purpose of the Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity. Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others.

Article 8 of the CRPD stipulates that States undertake to adopt immediate, effective and appropriate measures to raise awareness throughout society, including at the family level, regarding persons with disabilities, and to foster respect for the rights and dignity of these individuals; to combat stereotypes, prejudices and harmful practices relating to persons with disabilities, including those based on sex and age, in all areas of life; and to promote awareness of the capabilities and contributions of persons with disabilities. In addition, this article includes detailed pieces of advice as to how the awareness-raising process should be organized.

Articles 19-35 are essential in allowing CRPD to be used as essential platforms for planning national and local community-based MH policies and strategies.

Article 19 can be used as a benchmark of best practices on how people with mental disorders should live and be included in their local communities: States recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment of this right by persons with disabilities and their full inclusion and participation in the community, by ensuring that:

a. Persons with disabilities have the opportunity to choose their place of residence, where and with whom they live on an equal basis as others, and are not obliged to stay in a particular living arrangement;
b. Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in, and to prevent isolation or segregation from the community;
c. Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

The rest of articles stipulate, e.g. on the right for home and family, rights related to education, health, habilitation and rehabilitation, work and employment, adequate standard of living and social protection, participation in political life, cultural events, recreation, leisure and sport, international cooperation, and national implementation and monitoring. The main parts of these rights are operationalized in the seven booklets of CBR-guidelines for health, education, livelihood, social protection and empowerment as a cross-cutting component. Each component is divided into five key elements which are described with practical details (14).

For the MH reforms, the article 26 is relevant and important by stipulating on habilitation and rehabilitation: States shall take effective and appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life.

To that end, States shall organize, strengthen and extend comprehensive habilitation and rehabilitation services and programmes, particularly in the areas of health, employment, education and social services, in such a way that these services and programmes begin

at the earliest possible stage, and are based on the multidisciplinary assessment of individual needs and strengths, support participation and inclusion in the community and all aspects of society, are voluntary, and available to persons with disabilities as close as possible to their own communities, including rural areas. In addition, States shall promote the development of initial and continuing training for professionals and staff working in habilitation and rehabilitation services. Also, States shall promote the availability, knowledge and use of assistive devices and technologies, designed for persons with disabilities, as they relate to habilitation and rehabilitation.

Key concepts for rehabilitation and social inclusion.

Empowerment

Historically, people with mental health problems have lacked a voice. Neither they nor their families have been involved in decision-making on mental health services, and they continue to be at risk of social exclusion and discrimination in all facets of life (20-22). Empowerment theory and interventions link individual well-being with the larger social and political context, not only in the medical world. In the area of mental well-being the empowerment connects mental health to mutual help, trust, self-confidence, social relationships, and participation: *It engages us to think in terms of wellness vs. illness, competence vs. deficits, and strengths vs. weaknesses.* The empowerment research focuses on identifying capabilities (23). Empowered people with mental health problems make their own decisions, they have a say and are listened to (14,24). *The empowerment – disempowerment profiles* change according to the personal experiences and times of people's lifespan. The key message of the empowerment concept is that all persons have special strengths on which they can build up their lives even during the severe periods of different disorders.

Community-Based Rehabilitation

CBR is a common-sense strategy for enhancing the quality of life for people with disabilities. This is achieved by improving service delivery in order to reach all those in need by providing more equitable opportunities and by protecting their rights. CBR builds on the coordinated involvement of people with disabilities and their families (25). The collaborating international organizations ILO, WHO and UNESCO published first CBR documents during the1980s,

joint draft papers in the 1990s, and in 2003 and 2004. The CBR guidelines were published in October 2010. The guidelines are applicable and adaptive for all involved groups of people in all environments. Special guidelines for people with mental disorders were included in the supplementary booklet aimed at their inclusion in all aspects of life and activities in the community where they are living (22).

Recovery approaches

Users' choices and recovery are today at the forefront of mental health policy development. Recovery theories are based on the recognition that people with mental illness have the same wants and needs as everyone else (e.g. employment, education, housing, relationships, and recreation needs). In a recovery-oriented service system the users are included as full partners in every aspect of the service provision, including the setting of service priorities, sharing decision-making, and most importantly, having the option to agree or disagree with their treatment plans (i.e. full partnership). Recovery approaches as used in Scotland include the consensus statement in the USA, and the concepts of whole person recovery, recovery capital, and the Clubhouse model. For this analysis only CBR-type holistic methods are involved (26-31).

Social capital

Several studies have identified a positive relationship between the social capital and mental health as well as other related outcomes such as less social isolation, better social safety, lower crime levels, improved schooling and education, and improved work outcomes. The principal characteristics of social capital are: Community networks, voluntary action, civic engagement, participation and use of personal relations, local civic identity, sense of belonging, solidarity and equality and trust in the community. Three forms of social capital are identified, the bridging with weak ties, bonding with strong ties and linking social capital with influential external relations of a community (32-34).

Social cohesion

Social cohesion is based on the willingness of individuals to work together in small groups or at the community and societal levels to achieve common goals. Peer support is an important tool for strengthening mental health and for empowerment. There are multiple inputs to social cohesion on the community level, or to a society with a given level

of cooperation. The government policies are only one set of these inputs. Formal and informal civil society groups and associations, with ability to create and sustain the social and cultural capital, are also important components of the system. As important are the principles and values upon which a group's or community's activities are founded (35). International cooperation is an important part of social cohesion and a way of sharing information between different parts of the world. However, there are also risks in the ways of how socially cohesive groups and communities are organised. They can be based, *firstly* on the tight internal social bonds and order like in authoritarian groups and organisations; *secondly,* on the more instrumental and equal relationships with shared interests of members as in the users' and professionals' associations; and *thirdly,* on the wide external cooperation for the benefits of the whole group or organisation like in the best psychosocial rehabilitation models that are built upon the CBR – guidelines, e.g. the Clubhouse model.

Social inclusion–Social exclusion:

Social inclusion, like its counterpart social exclusion, has many dimensions: spatial, relational, and functional, and empowerment dimensions. Each dimension consists of more concrete elements, *e.g.* spatial dimension includes access to public and private spaces, physical location, and proximity and distances; relational dimension has elements of emotional connectedness, recognition and solidarity. Social inclusion is one of the components of social cohesion and it is an *outcome* of policies that promote equality (35).

According to Malcolm Shookner's concept of *Inclusion Lens* (36), people feel included or excluded *e.g.* in family, neighbourhood, education, labour market or other communities. Social exclusion and inclusion can be seen along cultural, economic, functional, participatory, physical, political, structural, and relational dimensions. All dimensions have elements on which it is possible to build up a self-assessment instrument for use in mental health service communities like Clubhouses.

Social integration: Social integration is the process of fostering societies that are stable, safe and just and that are based on the promotion and protection of all human rights, as well as on nondiscrimination, tolerance, respect for diversity, equality of opportunity, solidarity, security and participation of all people, including disadvantaged and vulnerable groups. It

has been repeatedly shown that social disadvantage is associated with an increased rate of mental disorders in the community (35).

The clubhouse model as a means to empowerment and social inclusion

The word "Clubhouse" derives from the work of Fountain House, the very first Clubhouse, founded in New York City, in 1948. Since its inception Fountain House has served as the model for all subsequent Clubhouses that have been set up around the world. The Clubhouse was organized as a support system for people living with mental illness, rather than as a service or a treatment program. Clubhouses offer people who have mental illness hope and opportunities to achieve their full human potential. Clubhouses demonstrate that people with mental disorders can and do lead normal and productive lives.

The Clubhouse International (formerly The International Centre for Clubhouse Development (ICCD) has been coordinating the Clubhouse development since 1994. The European Partnership for Clubhouse Development (EPCD, since 2013 the Clubhouse Europe) was established in 2007. In 2011 EPCD was registered in Denmark as an international association. Globally, about 350 ICCD Clubhouses are in action, of them about 90 in 22 European countries. New emerging Clubhouses are under planning, but in about 30 countries in Europe Clubhouses are not yet available. There are some Clubhouses which are not members of the Clubhouse International or Clubhouse Europe. In addition to North-America, Australia and Europe, Clubhouses are open also in Latin America and Africa, and in the People's Republic of China, India, Japan and the Republic of Korea.

The International Standards for Clubhouse Programs is the tool for quality management of these facilities. The accreditation procedure has evolved for the last 25 years, which means that the Clubhouse model is one of the forerunners in the quality management of the mental health rehabilitation and support models. Respect of human rights in all settings, equal opportunities, involvement and choices of users, living in the local communities like all others, human relationships and empowerment are the core of mental health policy recommendations. All of them have a high level of significance in the community-based CH practices. The fidelity of CH activities to its own standards is contributing to the good performance of Clubhouses: The quality-accredited CHs are more

effective and active in their support to social inclusion of their members (7,37).

The empowerment outcomes and social inclusion that result from participation in the Clubhouse programs and different activities emerge in several spheres of everyday life. Outcomes can be presented in the frame of CBR-guidelines. Positive changes in the original health and mental health conditions are widely reported; people with MH disorders have similar needs for learning and education than all others, and Clubhouses offer for their members a selection of different learning opportunities both in-house and externally like ICT skills, language courses, hygiene passport for catering works, support for education or training for a profession, etc.

Learning to cope in information society (internet banking, use of social media, basic ICT skills) and other educational outcomes such as getting new friends and peer support during the work-ordered day program in the Clubhouse are directly empowering CH members by strengthening their self-esteem, prospects for the future and motivation to take part in different activities also in the community they live in. Empowerment outcomes are linked with social inclusion in fields like advocacy support for housing, applying social security benefits and securing the adequate standard for independent living, job coach support for transitional and supported employment periods in mainstream workplaces. Recovery, empowerment and social inclusion are individual processes that are depending on a member's own readiness and choices of how she/he uses the possibilities which are available in and with help of Clubhouse (7).

Summarized scientific evidence on clubhouse model.

The Substance Abuse and Mental Health Services Administration (SAMSHA) in the USA has approved the Clubhouse model as evidence-based good practice (http://nrepp.samhsa.gov/ViewIntervention.aspx?id=189). Also in Finland the Clubhouse model is identified by the National Institute for Health and Welfare (THL) as a good practice based on several evaluation studies. According to international research the ICCD Clubhouses achieve the following tangible results for members and their communities (37-40):

- Key strengths of Clubhouse model are the sense of belonging and sense of community they provide which contribute to a member's social relations and peer support;

- Participation in Clubhouse activities promotes members' recovery;
- Several studies in different countries prove that participation in Clubhouse activities reduces hospital stays and days (60-80 %), and the use of other health and social services;
- Clubhouses are cost-effective by generating savings for healthcare and social agencies as compared with the pre-membership period of their members;
- Participation in work-ordered day, supported education, transitional employment and supported employment programs of a Clubhouse helps members to obtain training places in educational institutions and jobs in the open labour market;
- Participation in Clubhouse programs improves members' wellbeing and general health;
- However, if Clubhouse activities are not satisfying the needs of all users, other choices are needed.

Taking into account the comparison between key concepts of the intergovernmental MH policy recommendations and the Clubhouse Standards (7), the Clubhouse model fulfils requirements of the UN convention of rights of persons with disabilities, and works for the realization of these rights at individual member's life situations as a part of Clubhouse activities. In addition, the comparisons confirmed that the CH model fits in with the global WHO Pyramid Framework on an optimal mix of MH services, as well as with the CBR - guidelines and also with recent European MH policy programs.

CONCLUSIONS

The following may be considered as the main conclusions of the overview on common denominators and key concepts of the international mental health policy recommendations and their practical applications for promoting recovery and social inclusion of people with MH problems:
- The recommendable mental health policy approach is the combination of the WHO Pyramid Framework for optimal mix of mental health services and CBR-guidelines, with strong collaboration across different sectors and professions, all this in the context of the UN CRPD;
- The reality is that the existing mental health policies and services are far from the recommended optimal mix, the service pyramids are upside down; an urgent shift of MH paradigm is needed from institutional care practices towards more holistic and human rights-based variety of psychosocial

rehabilitation services in the communities;

- The greater part of mental health resources are used in hospital care, while the community-based services are still underdeveloped;
- Needs analysis in six countries indicated that service user needs for job opportunities and vocational training should be taken into account when the community-based optimal mix of services is being constructed. Users' low involvement in service development was a cause of dissatisfaction;
- An interesting finding of the needs' analysis was the rather low awareness of professionals and decision-makers about the international mental health policy recommendations, pointing out to the need for more effective awareness-raising campaigns;
- The membership in a Clubhouse generates savings by decreasing use of other social and health services, when compared with the pre-membership period, which supports the wider use of this model. Key strengths of Clubhouses are the members' feeling of belonging and a sense of community, and the quality management with due accreditation procedures;
- As a part of the combined mental health policy mix of the WHO pyramid framework and the CBR-guidelines, evidence-based Clubhouse model and other recovery approaches should be given opportunities to demonstrate their positive performance in all countries worldwide.

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