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**Community Mental Health Conference, BRNO
30-31 October 2018**

Whole Person, Whole Life-Whole System

History of Institutionalisation

**How we have tried to change the Thinking, Practices and
Systems**

Community Mental Health Development

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History of Mental Health Reform in the UK

1300-2018

The 4 milestone periods

- Genesis of asylums from 1377
- National Asylum System from 1840
- Community Care From from 1940s
- Whole Person, Whole Life-Whole System

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UK MH 1370-2018 Journey

The birth of the Asylum, Psychiatric Institutions

1300 In the UK, Bethlem hospital in 1377

Norwich, 1713, Manchester, 1766, Exeter, 1801

Rapid expansion in the 18th and 19th Centuries

To 150,000 beds in UK to 1950's

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The challenge to overcome the institutional system in the world

How we have tried to do this

- Reformers and human rights activists, Pinel, Beers, Rogers, Tuke, Dix, Weyer, Whitbread, Willberforce, Cooper, Connolly, Goffman, Laing, Szasz, Polak, Basaglia, Stein, Jones, Bennet, Barton, Antonucci, Tommasini, Rotelli, Dell'Acqua, Jenkins, Mezzina
- National Mental Health Laws, Policies and Strategies, UK, 1890, 1930, Poor Law 1959, 1968, 1975, 2001, 2004, 2015, 2017 Italy, 1904, 1960, 1978, 2016
- Mental Health Laws and legislation, present in many other countries, ? effect
- Human Rights legislation, International Convention on human rights MH 1991, WHO Qualityrights
- Community Mental Health Centers- innovation and good practice, CMHC's-USA 1960's, UK Paington 1980, Italy Trieste 1978
- Homecare teams, Amsterdam, Boston, Birmingham, Vancouver, Madison, Sydney
- User Movement, USA, UK, Italy, Europe, World
- Carer support organisations, NSF, Italy
- NGO's, community services, advocacy, lobbying, user support.
 - Present in all 192 countries

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Physical Restraint

John Connolly inspired by Robert Hill of Lincoln Asylum. On his appointment to Hanwell in 1839 Connolly proceeded to abolish it in a large asylum. Several English asylums were practising **non-restraint by 1844.**

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Some of the first places that started and changed the
Institutions

UK

Holloway Sanatorium, Virginia Water, Berkshire, Closed 1980

Warlingham Park, Croydon, first to offer community care, closed
1999

Exe Vale, Devon, Closed 1987

Banstead, closed 1988

Saxondale, closed 1989

Coney Hill, Gloucester, closed 1991

The Retreat, York, Private and open

Dingleton, Scotland, open doors 1946, closed 2001

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- Therapeutic communities, Tom Maine, Maxwell Jones, 1950's
- Acute Units in General Hospitals, 1960's++
- Fountain House, developed in 1940s New York, 55,000 worldwide
- Soteria House, Loren Mosher, USA, Switzerland, Sweden, UK,
- 24hr CMHC's, Trieste, Wales integrated community team with guest beds
- Host families, Boston, Madison, Lille and Hertfordshire, Wales
- Student/user shared accommodation, Lille
- Social cooperatives/ firms, Trieste, Brescia, Italy, UK, Poland and other countries
- Basic Needs For Mental Health and Development in 8 countries, they have helped 45,000 mental health users by developing work schemes:
India, Sri Lanka, Ghana, Uganda, Tanzania, Kenya and Laos PDR, Colombia.
- User run services, acute alternatives, Cornwall, Birmingham, Colorado, Madison
- Self help, Prato, Italy and many others
- Peer support, France, USA, UK, Poland, Italy and other countries
- NGO's – thousands of good practice services in many countries
- Open Dialogue, Finland, Trieste and UK
- Hearing voices across the world
- Research Programs on quality as well as quantity including by service users

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The Development of the User Movement

Has had a profound influence in changing thinking, services and practices

- UK,1620 Petition of the Poor Distracted People in the House of Bedlam
- France,1780 Jean-Baptiste Pussin
- 1848 in England, the Alleged Lunatics' Friend Society
- USA,1851Utica State Lunatic Asylum in New York, OPAL
- USA,1909 Beers founded the "National Committee for Mental Hygiene"
- 1970,s Peer run services, Insane Liberation Front, Portland,Oregon, Network Against Psychiatric Assault.
- Canada,1972 Mental Patients Association, Canada in 2007, called Interrelate.
- Voice of Soul is a user/survivor organization in Hungary.
- Germany,Organisation for the Protection from Psychiatric Violence,
- UK,1986 Survivors Speak Out, UKAN, MIND, Italy
- 1970,s Netherlands,Sweden,Denmark,Finland,Iceland,NZ,Aust, many more
- 1985 Kerala India
- ENUSP Europe 1991
- WNUSP World 2003, 120 organisations in 35 countries
- Self help groups, mutual support organisations, Italy USA, 7500,UK,500+

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Run Down and Closure of the Psychiatric Institutions

1954 Peak of numbers resident in English and Welsh Mental Hospitals. 150,000 beds

In the hospitals that pioneered community care, the numbers had been falling since 1948. Now the movement to avoid hospital admission and shorten in-patient stay began to effect overall numbers.

Day hospitals, community rehab houses, Out patient clinics, NGO's, anti-psychotic medication, scandals in the 30 Psychiatric hospitals

These had a profound effect on the numbers in the institutions.

From 1980-2006 All Psychiatric Hospitals in England and Wales were closed and community mental health services were implemented

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Essential Reform Objectives

- Change the thinking
- Change the practice
- Change the system

Emancipation = Equality = Responsibility

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CHANGE THE THINKING CHANGE THE SYSTEM

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CHANGE THE PRACTICE CHANGE THE PRACTICE

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CHANGE THE SYSTEM CHANGE THE THINKING

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Whole Person Whole Life-Whole System

A persons recovery, discovery is determined by their own desire and motivation supported by health, social care and a community working as a whole system

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- It was around this time that a group of radical texts began to circulate in Europe — Foucault's *History of Madness* (which also provided a critique of reformist approaches to madness and historical context), R.D. Laing's *The Divided Self* (which saw what was called schizophrenia as an understandable and even rational reaction to the pressures of modernity) and perhaps above all, Erving Goffman's *Asylums*
- *The Negated Institution: Report from a Psychiatric Hospital* (John Foot)

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The “great internment” described
by Foucault
gave way, in the 1970s, to a “great
liberation.”

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Community Mental Health in the UK

- Community Mental Health Teams, not all 24hr for populations of 60-80.000
- Crisis Teams in every NHS Trust and Health Boards
- Assertive Outreach Teams in every Trust
- Early Intervention Teams in every Trust
- Primary Care Teams in every NHS Trust and Health Board

As a community MH system of services, but?

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Mental health, learning disabilities and autism services

- At the end of March 2018, there were 1,254,365 people in contact with services; the majority of these 1,012,781 were in adult mental health services.
- There were 195,271 people in contact with children and young people's mental health services and 85,395 in learning disabilities and autism services .
- 280,613 new referrals were received into services during March and 1,705,404 care contacts were attended
- 20,314 people were subject to the Mental Health Act at the end of March, including 14,808 people detained in hospital
- Of the people in contact with services between 1 April 2017 and 31 March 2018 103,952 had an inpatient spell. Of these; 4,714 were aged 18 years or less , 78,883 were aged between 19 and 64, and 20,284 were aged 65 years or more.
- Between 1 January and 31 March 3,484 referrals with suspected first episode psychosis started treatment, of which 2,148 (61.7 per cent) waited two weeks or less.
- There were 8,343 open ward stays at the end of March in adult acute mental health inpatient care, and 5,722 open ward stays in specialised adult mental health services .
- Children and young people in contact with mental health services Between 1 January and 31 March 2,721 new referrals for people aged under 19 with eating disorder issues were received.
- There were 389,004 referrals active at any point during March for people aged under 19, of which 56,127 were new referrals and 41,559 people under 19 were discharged during the month
- Of the 1,191,779 in contact with mental health services at the end of March, 284,599 (23.9 per cent) were aged under 19.

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UK Policies and Plans, last few years

National Mental Health Service Framework 1998

Mental Health Plan 2002 Community Functional
Teams

New Horizons (2009)

A Whole Life Recovery approach

A holistic view of needs of people

No Health without Mental Health 2011

Mental Health Plan 2016

Not fully implemented

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Whole Person, Whole Life-Whole System Approach

Developed in 2000 in NIMH(E) to implement policies since 1975 and the National Service Framework

Approach to bring together;

- Biological
- Psychological
- Social determinates of Health and Mental Health
- Anthropological, Meaning and Culture
- Philosophical, Critical Thinking. Dialogue
- Whole Life, Recovery Paradigm
- Whole Systems Thinking, MH Unitary organisation, services, management and resources
- Education and Knowledge, Sharing and Learning from International best Practice

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Whole Person, Whole Life- Whole System

The Whole Person, Whole Life-Whole System Recovery and Discovery approach is founded in **human values** and their application by the service user, families and the community, professionals and the service itself.

- >Recognition of the **power** of institutionalisation as reflected in stigma, practice and outcomes
- >It requires a **paradigm shift** in thinking from pathology and illness to whole life needs, whole life stories and a recovery and discovery journey for the user and family member
- >It believes in the **power** of individuals to self determine their **Whole Life and future**
- >Peoples **life stories**, events and experiences are at the centre of their problems and their solutions

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The Whole Person, Whole Life-Whole Systems Approach

- This focuses on the need to help and support patients(users) to be able to continue or regain a whole life in all its domains, wellbeing, health, socially included, access to education, work, housing,cultural and leisure activities, sports, faith, etc.
- This cannot be achieved by the health service on its own and by only replacing psychiatric hospitals with isolated community mental health facilities.It needs a Whole System developmental approach.
- Therefore there needs to be developed a MH **community whole system** with an overall common purpose building partnerships with various local authorities, community organisations, users, family members and business leaders.
- Based on Recovery, Discovery Values, Principles and Practice

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Retain and encourage users and family members with professionals to,

- Control and responsibility
- Hope
- Self esteem
- Self determination
- Sense of purpose
- Achievement and Productivity
- Citizenship and Sense of belonging
- Meaningful Relationships
- Social inclusion

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- >The fundamental importance of trusting relationships
- > Recovery is possible for everybody
- > Mental health belongs to the person and the community and needs to be addressed through a whole life - whole system approach
- > Peoples whole life domains can only be fully addressed by engaging with and building partnerships within identified local communities

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Effective practice is founded on:

- >the therapeutic alliance established between the professional, user, family member on a mutual and reciprocal relationship, equal access to information, knowledge of and capacity to utilise best practices
- >Its objective is to achieve health and well-being regardless of the degree of disability or distress of the individual.

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- >the right of the user to choose the worker, the form of recovery support and therapeutic intervention that best suits the stated needs of the individual
- >continuity of a consistent relationship and approach across all parts of the services and communities, only achieved by an integrated system
- >the family and/or other significant people should be actively involved in the recovery/discovery journey

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The Whole System

- Mental Health Service components, CMHC's, CMHT's, Psychiatric hospitals, General Hospitals MH departments, out patient clinics, GP's, Public Health working together as an integrated and interrelated whole MH system
- Embrace and harness individual and community strengths, resources and opportunities to build a whole community system
- Enable individuals to continue or regain a whole life in all domains:

wellbeing, health, social networks, education, work, housing, art & cultural, faith, sport and leisure

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A health system and services cannot achieve a **Whole Life-Whole System** approach on its own.

A community whole life system needs to be developed with a **common purpose** that is understood and agreed

The agreement must be formed with **communities** including family members, service users, community organisations and public bodies

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System thinking is a discipline for seeing *wholes* not *holes*

The essential framework is:

- > developing inter dependence and interrelationships rather than static and separate parts.
- > Embracing all the values and principles of the recovery, discovery approach by all services and staff

A shared culture

- > All parts of the system have an important contribution in achieving the overall whole person, whole life purpose

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A Persons' Whole Life Domains

- A whole life in all respects
- Family, friends and community
- Health and wellbeing
- Education and skills
- Occupation training, placement and support
- Housing and support
- Sports and Leisure
- Art, culture and faith
- Treatments and therapies
- Self help. Peer support
- Psycho-education

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Challenges for Services

Many people in mental health services have ***lost hope for the future***

The system has ***focussed on problems and disorders*** and has ***eroded aspirations***

There is a ***culture of low expectations*** that effects people who use services as much as those who provide them

There is a fragmented service system, working in silos

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Moving Forward

- move away from preoccupation with security, risk and no hope.
- Recognise that social determinants are key causal factors to a persons' mental health and the opportunities for their recovery and discovery.
- Develop a whole integrated system in mental health services, with collaboration and partnerships
- Prioritise common purpose and joint ownership by engaging together with the community

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What are the main challenges for you as a service user, family member, worker, organisation in developing this Whole System approach?

- > What advantages could the approach have for yourself or the people and the community you serve?
- > How could this approach be developed in the Czech Republic?

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Personal Reflections

- How do my beliefs, assumptions influence my practice?
- How does our practice enhance peoples lives
- What do we do to encourage self determination and empowerment
- How do we develop rapport, relationships and hope
- How do we improve the integration of services and communities

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Recovery and Discovery practice

Recovery and Discovery practice is about enabling and assisting the active participation of people in their own life journey.

- This approach involves assisting people to find the time, space and opportunity to identify their own recovery and discovery goals and meet them.
- It asks the “helping community” to work in ways that are fundamentally different.
- Recovery and Discovery practice is not something that is considered as an after thought or bolted onto existing practices.
- It asks us to think of our value framework and invites us into an "expansive space" with people in distress. Time and Space.
- Inviting people to create their own opportunity within their space, where the goal is to enjoy a whole life (where citizenship is more real, with more meaning and purpose in their lives).
- This approach requires the “helping community” to intuitively work in ways that can hold a space for this to occur. Providing traditional and fixed models do not provide the opportunities for this to occur. In fact they may only serve to contribute to shutting down the space where people can have opportunities to commence and continue their recovery and discovery journey.
- Recovery and Discovery practice is therefore as much a learning process for practitioners, carers, and the wider community as it is for people in distress.

IMPACT

Emancipation, Equality and Responsibility

Values, Principles and Practice

A New Paradigm in Taking the Reforms forward

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EMANCIPATION

- The guiding principle and application of 'Freedom First' in mental health services, is not completed just by the process of deinstitutionalisation.
- It is an ongoing priority in community and hospital services and practices.
- For a persons freedom in services, a democratic process is a prerequisite for a therapeutic experience.
- Services must hold this as a central guiding principle for determining ways of working with and alongside the person and their social network.
- This has implications for thinking, culture and practice. "**Nothing about the person without the person**" is more than a statement of intent it needs to be **Embedded** in practice.
- This has implications for service organisations including how they enable the service user to have choice in treatments

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- **This also has consequences for the way in which services work with the person and how information about the person is gathered, held and decisions reached.**
- **Inclusion and reintegration of people, who, because of their mental health problems, continually deal with exclusion mechanisms in society, is an ongoing process.**
- **Apart from the legal right to freedom, the restoration of social relations is essential for recovery and discovery.**
- **Isolation by locking people up counteracts this.**
- **In some enlightened services it is therefore a recurring, conscious decision not to lock up people, this is 'open doors' at all time.**
- **In our aim of reducing the hospital capacity and building a good support system in the community, another mission emerges: reducing coercion in treatment, stopping in-patient practices of locked doors, seclusion, restraint and over medication**

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- **Shaping good alternative acute and crisis services where people can have time and space for reflection in times of crisis is essential if we are going to address the whole life needs of people.**
- **The present services, outpatient clinics, acute units, community teams, and intensive treatment is no longer sufficient, We need a new Acute and Crisis Whole Life-Whole System based on the principles of freedom, choice, co-production, emancipation and self determination.**
- **A service user to be considered emancipated has to be independent, free and autonomous in their decision-making.**
- **Emancipation is linked to the process of self-reflection, to acquiring new knowledge, motivations, values and goals, which will free the individual from preconceived and impairing beliefs**
- **Emancipation involves setting the service user free from the control exercised by nurses, doctors, psychologists, occupational therapists, social workers, managers and organisations (acting as institutions). A person with a mental health issue needs to have greater knowledge and understanding of their whole life situation which can support individual emancipation and increases self-management.**

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EQUALITY

- **To attain social inclusion, the focus must be on equal citizenship.**
- **This concept combines classical human rights (such as liberty and equality) with civil rights such as the right to education, employment, social security, housing, etc.**
- **The problem with mental health law is that too many people have their liberty curtailed. This needs to be addressed by a fundamental review of the mental health legislation**
- **This is done in three ways: by strengthening the position of the individual (through knowledge, education, skills and social networks)**
- **By strengthening the ‘social fabric’ of the individual’s environment, through social corporations, anti-stigma programs, Whole System development; and addressing the human rights of the individual.**
- **Because of the Whole Life-Whole System approach, these three ways are intertwined organisationally and in the daily practice of mental health professionals.**

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EQUALITY and CITIZENSHIP

- This requires a new vision on how personal support is organised and funded.
- **Reciprocity:** In cultural anthropology the principle of reciprocity is described as a way to create and perpetuate equal relationships of exchange.
- An active giver (professional) and a passive receiver (service user) have an unequal (power) relationship.
- The creation of situations where a service user who receives personal support through co-production works more effectively, and also provides opportunities for education, employment, housing, social support and is more likely to shape equal relationships and better outcomes.
- This will promote the empowerment, recovery and discovery of users and family members.
- Following this line of reasoning, the next step should be to swap the attitude of professional distance for a more personal relationship founded on connectedness, continuity and trust.
- This aligns with values and principles for supportive recovery and discovery approaches.

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RESPONSIBILITY

- People have a responsibility for determining for themselves the lives they lead and their own wellbeing.
- All too often services and professionals prevent people being responsible adults, in hospitals but also in community services. Mental Health Laws in collusion with this.
- This is particularly relevant when there are concerns about the persons mental health and well being.
- The importance of shared responsibility (users, family members, professionals, organisations) in taking risks and being jointly accountable.
- The services should encourage and support the important principle of self determination by providing services and practices that support and underpin this.
- **Choice:** Service users should be able to determine their own recovery, discovery plan in collaboration and co-production with their workers, families and significant others.

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RESPONSIBILITY

- **Service providers should accept that recovery/discovery is a process requiring every service user to be regarded as a unique individual and the course of this journey has its ups and downs**
- **Their wishes, needs and hopes should be at the centre of service provision and practice.**
- **Relationships:** The service user should be able to determine the person they want to work with based on the importance of reciprocity in a trusting relationship.
- **Ownership:** Service providers should accept that the service users are experts in their own life experience and this should be the foundation of a therapeutic alliance with the expert by profession.
- **Opportunities:** The service user should have available whole life opportunities based on their unique needs.

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Today, institutions and institutional thinking and practice in the world as well as Italy and the UK is still “alive and well”. The biological approach and model is also still dominant

- We need to replicate and implement the good practices and innovations in more services, practices and services, communities , places
- We need to identify existing and help find new reformers, champions,pioneers, advocates for change and reform. Can you identify them in your country?
- We need to work more together through stronger networking, lobbying and influence policy, services, practices, research
- We need to expose bad practice,abuse, neglect that is still widespread in institutions and communities in many places and countries
- We need to promote a Whole Person, Whole Life-Whole System and Recovery philosophy, concept, practice and action in all our work, Emancipation, Equality and Responsibility
- We need to be aware of the dangers today of the market economy in health that leads to competition not collaboration

This we need to do, to overcome and finish off the powerful influence of the belief system(people cannot recover) that created and still perpetuates Asylumdom and its power over people

ONCE AGAIN IT IS ALL OUR RESPONSIBILITY