

# Promoting Mental Health in Intellectual Disability:

## Building bridges between theory, research and good practice

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### Introduction

The third Study Day on Disability, proposed by the “Association des Parents d'Enfants Mentalement Handicapés” (APEMH) and supported by the “Fonds National de la Recherche Luxembourg” focused on the topic of mental health and aimed at building links between theory, research and good practice.

Mental Health is a most current topic in the field of intellectual disability (ID). A good mental health, as well as access to service systems for prevention, treatment and aftercare, should be guaranteed for all people. Unfortunately, persons with ID are often not considered when it comes to defining or using necessary services or getting access to specially trained professionals, although the population of persons with ID is at special risk for developing Mental Health Problems.<sup>1</sup>

Assessment tools, diagnostic criteria, the modus of assessment and/or treatment for the general population cannot be used without adaptations for people with ID. Systems in charge with mental health have to develop specific competences to adequately meet the special needs of this population.

Since various professions are concerned with the topic of MH in PwID, it is important to “pool” knowledge, as well as to create and maintain networks throughout all professions and countries, including:

- Researchers
- Policy-Makers
- Experts (Psychiatrists, Experts on ID)
- Nursing-staff and frontline-carers.

### Criteria for ID

ID is defined in a variety of legal, professional and research contexts. Most criteria for ID usually refer to (a) significantly below average intelligence, (b) deficits in adaptive behaviours that (c) occur during the developmental period. Definition of ID has been adapted in regular periods. This reflects developing social practices and service ideologies, changing test characteristics, population changes and changes in incidence and case finding.<sup>2</sup>

Dr. Marco Bertelli offers another view on ID, and emphasizes other aspects. ID should not be regarded as a disease or as a disability but as a syndrome grouping

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<sup>1</sup> The relationship between challenging behaviours and psychiatric disorders in people with severe intellectual disabilities. Hemmings, C. (2007). In *Psychiatric and Behavioural Disorders in Intellectual and Developmental Disabilities*, ed. Bouras, N. Cambridge: Cambridge University Press, pp 40-44.

<sup>2</sup> *Psychiatric and Behavioural Disorders in Intellectual and Developmental Disabilities*, 2nd Edition Edited by Nick Bouras, King's College London

(metasyndrome). It includes a heterogeneous group of clinical conditions, ranging from genetic to nutritional, infectious, metabolic or neurotoxic conditions. The ID metasyndrome is characterized by a deficit in cognitive functioning prior to the acquisition of skills through learning. The intensity of the deficit is such to interfere in a significant way with individual normal functioning as expressed in limitations in activities and restriction in participation (disabilities).<sup>3</sup>

## Criteria for mental disorders

In diagnostic classification of mental disorders the DSM (Diagnostic and Statistical Manual of Mental Disorders) and the ICD (International Classification of Diseases) systems are used mainly.

The ICD-10 defines mental disorders as:

Clinically significant conditions characterized by alterations in thinking, mood (emotions) or behaviour associated with personal distress and/or impaired functioning. Mental and behavioural disorders are not just variations within the range of "normal", but are clearly abnormal or pathological phenomena. One incidence of abnormal behaviour or a short period of abnormal mood does not, by itself, signify the presence of a mental or behavioural disorder such abnormalities must be sustained or recurring over time and they must result in some personal distress or impaired functioning and are also characterized by specific symptoms and signs, and usually follow a more or less predictable natural course, unless interventions are made.<sup>1</sup>

The application of the concept of a mental disorder to people with ID presents several difficulties.

Recognizing the limitations of these manuals adapted systems have been developed such as the DC-LD (Diagnostic Criteria for Psychiatric Disorders for Use with Adults with Learning Disabilities), specially for that population. Although a lot of improvement can be seen nowadays within the diagnosis, the reliability and validity of a psychiatric diagnose is still a big question for persons with ID. (*Anton Dosen*)

## Mental health

The management of mental health disorders in persons with ID is often paradoxical; the professionals (psychiatrists) still use the same categorical approach for persons with ID, though these categories are only validated for the general population. The first step should be to specify the question, what we are talking about; is it a question of mental health, mental illness or behaviour disorder. More attention should be focused on mental health.

For this purpose the definition of mental health is essential. At the moment several different definitions are known. Mental health:

- State of complete physical, mental and social wellbeing, not just the absence of disease.
- Some defines mental health as a state of homeostasis.
- The ability to love and to work
- Psychological well-being and cognitive functioning
- A state of well-being in which the individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community (WHO)

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<sup>3</sup> 'Mental Retardation' or 'Intellectual Disability': Time for a Conceptual Change. Luis Salvador-Carulla, Marco Bertelli. *Psychopathology* 2008;41:10-16

Psychiatric disorders as well as problem behaviour can be seen as a disturbance of mental health. Mental normality and abnormality should be marked as end points of a continuum; the differences are quantitative, not qualitative.

Certain problems are still present, such as the question of rehabilitation –following up the development of these persons is essential. New ways and new methods should be developed in this field. There is also a lack of systematic research within the field of mental health for people with ID. Further work needs to be done in the field of prevention too.

It is clear, that the knowledge we have of the traditional psychiatry and psychology of the population in general is not sufficient to give answers to all the relevant questions involved in caring for persons with ID.<sup>4</sup> (*Anton Dosen*)

There has been a change of the focus from mental disorders towards mental health in persons with ID. Understanding the state of mental health is essential in order to get an understanding of mental disorders or problem behaviour. (*Germain Weber*)

## **The Overlap between Problem Behaviour and Psychiatric Disorders**

Mental Health can be impaired by psychiatric disorders as well as by problem behaviour. The interrelations and forms of overlap of these two concepts are not sufficiently defined up to now. Different researchers and experts express different opinion concerning this topic. Moss, Kiernan and Emerson<sup>5</sup> defined three different ways relationships between CB and psychiatric conditions may work:

- 1.) CB could be atypical symptoms of a psychiatric disorder
- 2.) CB could occur as a secondary feature of a psychiatric disorder
- 3.) A psychiatric disorder could produce the basic conditions for showing PB. PB is maintained through operant conditioning.<sup>6</sup>

Dosen, Gardner, Griffiths, King and Lapointe<sup>4</sup> stress the point that PB should not be regarded as primary symptoms of a psychiatric condition, but rather as a secondary consequence of a possible psychiatric disorder.

Marco Bertelli argued in his presentation that correlation studies between psychiatric disorders and adaptive behaviour in adults are lacking. This brings up the question what kind of new knowledge correlation-studies would generate. Using this method, one can easily produce data and figures about mere interrelation of these two concepts, which is most valuable and interesting to know about, but doesn't give any hint about the kind of interrelation, supposed causalities or onset mechanisms. Whereas it is these theories that are of most interest, since they could lead to

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<sup>4</sup> Mental Health and Mental Illness in Persons with Mental Retardation: What Are We Talking About?, IN: Mental Health Aspects of Mental Retardation. Anton Dosen. Edited by Robert J. Fletcher and Anton Dosen. Lexington Books, N.Y. 1993.3-17.

<sup>5</sup> The relationship between challenging behaviours and psychiatric disorders in people with severe developmental disabilities. Moss, S., Kiernan, C. & Emerson, E. (1999). In Psychiatric and Behavioural Disorders in Developmental Disabilities and Mental Retardation, ed. Bouras, N. Cambridge: Cambridge University Press, pp 40-44.

<sup>6</sup>Challenging Behaviour: Analysis and Intervention in People with Learning Difficulties. Emerson, E. (1995). Cambridge: Cambridge University Press.

specialized prevention and intervention methods and could be used as a basis for creation of needed services.

Special attention has to be paid to the method of assessing and diagnosing PB and psychiatric disorders. In interpreting results of studies that try to detect the mechanisms of interrelation between CB and psychiatric conditions, it is crucial to know how these mental conditions were assessed and what instruments were used.

## Models of Classification

Models and Classification Systems concerning intellectual disability use mostly either the concept of a quantitative or a qualitative approach. Whereas the qualitative approach uses different categories to classify people, the quantitative approach can be seen as a continuum, where every person is placed on the same qualitative category, but with different characteristics. Getting a Psychiatric Diagnosis of ICD-10 or DSM-IV is clearly qualitative, whereas examining the intensity of needed support of an individual is quantitative.

In the presentation of Marie-Claire Haelewyck and Jean-Philippe some important existing Models, including the International Classification of Functioning, Disability and Health (ICF)<sup>7</sup>, the Disability Creation Process (DCP)<sup>8</sup>, the system of the American Association on Mental Retardation (AAMR)<sup>9</sup> and the Supports Intensity Scale (SIS)<sup>10</sup>, were introduced.

Special emphasis was given to an ecological model, which concentrates on the interaction between the individual and the environment and recognizes the fact that both, the individual and the environment, are changing constantly.

Positive feature of the ecological model:

- special emphasis is given on risk- and protective factors
- various other models can be integrated in the ecological model
- the model bears the possibility to derive models for research purposes, as well as for intervention

## Policy and Service Systems

There are still weak spots within the care-system. Further improvement is needed in terms of the generation, exchange and bundling of knowledge and experience.

### More attention is needed for

The communication between the clients and the professionals as well as in between the different professional disciplines is needed in order to reach a better functioning system and to avoid a narrow perspective.

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<sup>7</sup> International Classification of Functioning, Disability and Health. (2001). World Health Organization, Geneva.

<sup>8</sup> The Quebec Classification Disability Creation Process, Québec, International Network on Disability Creation Process (INDCP)/CSICIDH. Fougeryollas, P., Cloutier, R., Bergeron, H., Coté, J. & St.Michel, G. (1998).

<sup>9</sup> Mental Retardation: Definition, Classification, and Systems of Supports, 10<sup>th</sup> Edition. American Association on Mental Retardation. (2002). Washington, DC: American Association on Mental Retardation.

<sup>10</sup> Supports Intensity Scale. Thompson, J. R., Bryant, B., Campbell, E. M., Craig, E. M., Hughes, C., Rotholz, D., Schalock, R. L., Silverman, W., Tassé, M. J., & Wehmeyer, M. L. (2004). Washington, DC: American Association on Mental Retardation.

Learning potential for the person with ID should be taken in consideration throughout the whole process. The usage of medication should be dependent on an evaluated evidence-based indication.

In order to promote the social inclusion of the persons with ID enlarging the person's social network is essential. Involving the community, the neighbourhood etc. in the person's life to avoid a closed sub-community. Cooperation with the parents and their participation in the treatment and care process should be enhanced. Attention should be focused on the family and the relatives of the person.

### Mental health

The first step of the process is meeting the person and to try to get to know him from any possible perspective. Meet the wishes, dreams, needs and possibilities of the person as a particular individual. Only after we know who we are concerned with can we start any kind of treatment, therapy or support provision. We should constantly look for new perspectives in regard to the possibilities and abilities of the person.

### Positive developments

There has been a remarkable shift in the vision and paradigm within the last few years. The emphasis turned from care to support (supports paradigm); from the Quality of Care towards the Quality of Life; from facility-centred services to an individualized community support approach in services and supports for persons with ID<sup>11</sup>. That means in practice looking at the actual needs and possibilities of the client. The core task for a service provider for people with ID is to provide support in living and work, daily activities to the clients in order that their quality of life is optimised.<sup>12</sup> By providing more active and more elaborate daily programs, opportunity is given to personal development and self-determination. In this approach the emphasis is on the strong points and competences of the person; they can have perspective and a rational purpose in life.

### Problems

There is a shortage of psychiatrists, in particular those who work for persons on lower developmental levels. There is a gap between the regular care for mental health and the care for persons with ID

Organisational problems occur of the care for mental health within the care for persons with ID and mental health problems. There is a shortage of prevention in the field of mental health problems.

## **Steps in conducting research concerning Mental Health in People with Intellectual Disability**

Research is an important step in generating facts and data, which can be used to evaluate and change existing concepts or services concerning mental health of people with intellectual disabilities. It's crucial to have reliable data and figures when it comes to convincing policy-makers of needed changes and improvements in this sector. Most speakers of the various countries that attended this Study-Day (e.g Hillery, J. or Derouaux, M.) agreed upon the fact that research has to be done, and should be seen as the first necessary step to plan and realize services. This starts with the prevalence

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<sup>11</sup> Quality of Life Versus Quality of Care: Implications for People and Programs. Isabel De Waele, Jos van Loon, Geert van Hove, Robert L. Schalock. Journal of Policy and Practice in Intellectual Disabilities. 2005 September/December, 229-239.

<sup>12</sup> A Person Centered Support System. Improving Quality of Life Through Supports. Dr. Jos van Loon

of people with ID who are afflicted with mental health problems and points out the necessity of good tools for assessment and diagnosis.

Anton Dosen states in his presentation two basic steps of scientific thinking:

1.) Taxonomy and classification of phenomenon

At a very first step one has to define the concepts he/she is working with. Although this seems to be obvious, the taxonomy and classification of mental health problems in people with ID are not that easily found. Nevertheless, every researcher has to start and work with a definition of these concepts.

2.) Process oriented thinking: emphasis on development (explanation and understanding)

The second step includes understanding of the concepts and taking into account the development of a person and reciprocal effects of influencing factors.

Since this topic affects professional of various fields, a multi-professional team and/or specialists on the specific topic of mental health of persons with ID should work together on research projects. Unfortunately this bears problems. In Luxembourg there are hardly any psychiatrists interested to work on this topic (Ceusters, E.). In Austria no academic curriculum exists for psychiatrists, who want to specialize in intellectual disability. (Weber, G.) These academic curricula would be most important, since conducting and getting funding for a research projects in a specific field is often dependent on the existence of an academic curriculum.

Clearly, the process does not stop with doing research and creating figures and data. This data has to be used and should be transferred to practical work.

## Conclusion

We have to consider and agree on the fact that Social and Disability Policy is first of all a Human Right Policy : Mental health and/or challenging behaviour issues are a major risk for segregation an unequal opportunities for People with an intellectual disability!

Mental health as well as specialized mental health services, including prevention, intervention and after-care, is of most importance for people with intellectual disabilities. A good and stable mental health is an important goal for every person, with or without disabilities, and is a basic precondition for a successful integration and inclusion of persons with ID.

Mental health can get affected by problem behaviour as well as by psychiatric disorders. The prevalence of both these psychopathologies is higher in people with ID than without ID, which should lead to the conclusion, that special emphasize could be given to prevention and treatment of this very population.

Since the topic of mental health for people with ID affects professionals of various fields, a multi-professional team is necessary for assuring qualitatively and quantitatively sufficient service structures. The basis for setting up service structures are research activities, including reliable figures about prevalence of people with ID and mental health problems as well as evaluation about what kind of service structures are needed.

Reproducing Dr. Germain Weber's final conclusions and outlook, we could mention **a general recommendation** to develop

- a **national strategic health plan for people with ID** (mental health in ID) including all the stakeholder from the field (users included), based on UN's 2006 Declaration on Rights for People with Disability (Article 25) combined with an **Plan of Action** and assure a commitment for monitoring and evaluating (to avoid that it remains on a paper work level)

Futher on and in a more detailed way:

#### **In the domain of Prevention, we should**

- set up a quality system for supporting and caring people with intellectual disability in their every-day-life based on an understanding for a good quality of life and mental health
- define a person-centred approach, assess needs of support and intensity of support in an individual way;
- set up a quality assurance system in service provider structures for mental health needs of people with ID

#### **In the domain of Services Provision we should**

- include in the national health system qualified structures for supporting people with intellectual disability who show mental health needs (new commitment);
- opt for an expert pool (extern consultants, mobile teams)
- look for intervention and therapy approaches assuring continuation and congruency

#### **In the domain of Training we should**

- develop specific modules on mental health in people with ID within the initial training programmes for front line (educational and care) staff in the disability field with clear competence profiles
- Opt for translational training: transform knowledge to practice, importance of case studies
- Define post-graduate qualification for professionals like psychiatrists, psychologists, educational scientists

#### **In the domain of Evaluation and Research**

- we should create a supportive environment for evaluation and research in the field of mental health and ID including results from recent research, which offers new information for explanation and understanding

It's promising that experts from all European Countries participating in this Study Day, expressed the understanding of importance of the topic of mental health and mental health services. In the years to come it may be possible to introduce necessary changes to existing systems, so that the number of mental health problems in people with intellectual disabilities will decrease, and people with ID could be better integrated and included and could benefit from an increased quality of life.