European Training Modules for Staff Supporting Individuals with Dual Diagnosis

The TRINNODD project outcomes
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1. Introduction and Summary

The literature indicates that training for support workers can have a positive impact on the intensity and pervasiveness of psychopathological and behavioural disorders in people with Dual Diagnosis (DD: intellectual disability combined with mental health problems). Despite this, training programmes are still rare or inadequate across most European countries. A shared body of updated knowledge for daily practice is also lacking.

In order to answer those needs, the above partnership set up the TRINNODD project (TRansfer of INNOvation on Dual Diagnosis). TRINNODD was a 2-year European project (2008-2010) funded by the Leonardo da Vinci Lifelong Learning Programme which aimed to update the previous TRIADD product www.triadd.lu and to transfer practice knowledge about problems related to DD to new target groups in Italy, Spain, Portugal and Romania.

The project progress was divided in 5 phases:

FIRST PHASE – Needs assessment
A 17-item questionnaire was completed by 170 experienced staff members supporting people with DD. They were randomly selected in different settings across the 4 European countries participating in the project. They were asked to describe the context of their work, the subjects related to DD that could have been useful to them, the principles or practices their team was following and the specific training they had received. Considerable divergences emerged between Romania and other countries, while minor differences were noticed for Italy, Portugal and Spain. Four main areas of innovation were identified: emotionality, quality of life, vulnerability and training methodology.

SECOND PHASE – Development of training modules
Within the four settings above, the following subjects were identified as a priority for training: stress prevention, assessment of individual and family quality of life, complexity of individual vulnerability, environment (family and community), different theoretical approaches to intellectual disability.

On the basis of these conclusions, recommendations from former TRIADD training modules and results drawn from recent research studies, new training units including these aspects were designed by TRINNODD partners.

THIRD PHASE - The delivery of training sessions in Italy, Portugal, Spain and Romania
The training modules were organised in partner countries between November 2009 and March 2010. The sessions lasted 20 to 30 hours and were delivered to health care professionals and frontline carers (doctors, nurses, psychologists, therapists, rehabilitation technicians, social workers, educators). The training modules focused on the 4 areas of innovation identified in the TRIADD project and on some areas identified as specific to particular countries.

An unplanned bonus to the project was the opportunity to run a second course of training in late 2010 in the partner countries following the development of a core curriculum.

FOURTH PHASE - The evaluation process
The training sessions were evaluated very positively by trainees. A long-term evaluation was made 6 months after the course delivery in order to assess the impact of the modules on trainees daily practice. A final evaluation of the level of satisfaction of users, families and professionals was planned for the very end of the project lifetime.

FIFTH PHASE – Dissemination of the project results
The project achievements were published in a newsletter, a brochure and on the project website www.trinnodd.eu. A variety of valorisation activities took place in each of the participating countries during the project. A final dissemination conference was held in Romania in September 2010. Partners also shared the project results in their own country and within European and international networks through presentations at conferences.

Two main valorisation seminars were held in Lisbon (May 2010) and Luxembourg (November 2010). The project partners took part in the Third Study Day on Disability on the subject of “Promoting Mental Health in Intellectual Disability. Building bridges between theory, research and good practice”. This seminar was organised by partner APEMH with the support of FNR (Fonds National de la Recherche - Luxembourg) on 12th May 2009 in Remich (LU) and gave an overall state of the art on issues directly linked to the TRINNODD themes. (see report in appendix)
2. Transferring knowledge into practice

Knowledge can be defined as “available information that is new to the people or organisation for whom it is intended: it includes research findings, prevention guides, manufacturing processes, work methods and innovations” (Roy M., 1995)

How do we get knowledge, evidence and experience from the pages of books, journals, the specialist knowledge held in the heads of highly trained professionals into the realm of the direct care and wellbeing of the individual? The transfer of research findings and knowledge into practice is “often a slow and haphazard process” (Graham et al, 2006). Although there is an increasing body of evidence of the greater prevalence of mental health problems in people with intellectual disabilities, the aetiologies, management and long term outcomes of such conditions, this knowledge may only be contained within professional networks and organisations and does not reach the world of the individual with intellectual disabilities, their families and carers. This separation, which Graham et al refer to as the Knowledge to Action gap, has become further highlighted with the increasing emphasis on health and social care that is evidence-based, cost-effective and accountable.

There are many different terms applied to this area including knowledge transfer, knowledge translation, knowledge exchange, implementation, dissemination and diffusion. Simple transfer of knowledge from the evidence base to an individual or group, either directly or through an intermediary (e.g. educator, facilitator, trainer, translator) is less effective in ensuring the tailoring of information to a learner's needs, attention to the way in which such knowledge may be used and the impact of the acquisition of knowledge on the learner’s area of work or influence. It also does not address the need for these issues to inform future knowledge acquisition and creation and the further development and modification of the modes and content of effective knowledge transfer. A reciprocal, or exchange process is required, in which there is a reflective cycle of continuing dissemination, evaluation, learning and modification focussed around the needs of the target population which are not necessarily confined to the identified learners but might include those within their sphere of work or influence, those on whom the cycle may have an impact that initiates further processes of knowledge generation and dissemination.

The defined aims of the TRINNODD project were to:

- Make a link between the recent research results and the concrete experience of frontline staff,
- Develop a new and interactive training material with the help of research partners. The training material will focus on the needs of users and on the improvement of their quality of life,
- Transfer this new training product to new target groups and in new geographical and cultural realities,
- Develop an evaluation tool to measure the short- and long-term impact of the training modules.

In the context of the developing TRINNODD project, it became clear to partners that the aims and the methods of this and the previous TRIADD project could be conceptualised within a model of knowledge transfer and exchange similar to that described by Saini and Brown (Saini, 2010) (fig 1).
Knowledge Creation:
The project was established on the principle of transfer of experience and recommendations from TRIADD:

The recommendations drawn from the TRIADD project were the basis of the TRINNODD innovative approach:

- Focus on stress prevention strategies for PWD and staff
- Focus on the concept of Quality of Life
- Ensure involvement of trainees and interactivity during training course (preparatory work and work on case studies)
- Ensure a follow-up of the training (short and long term evaluation)
- Provide resources for staff for further professional development
- Involve psychiatrists in the training course
- Focus on the pharmacological intervention aspect (early detection of warning signs, use international recommendations on medication)

The partner co-ordination group, involving a range of professionals that included psychologists and psychiatrists also drew on their collective clinical experience and knowledge of the relevant literature to establish the form, content and evaluation of the project. Relevant literature on the mental health of people with intellectual disabilities, quality of life, guidelines for the use of medication and the assessment and management of challenging behaviour were amongst the evidence base on which elements of the training modules were constructed (see Bibliography). Fundamental to the project was the information obtained from the needs analysis carried out through questionnaire surveys of staff involved in the support of people with intellectual disabilities and also of family carers and individuals with intellectual disability themselves (see Chapter 3)
InFormation: A Model for Knowledge Transfer and Exchange (KTE)
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Suggested Citation
The project was mindful that the evidence base was limited in some areas and also that issues such as diagnostic criteria, concepts of mental health and in particular, quality of life would vary from country to country. Similar variation might be expected in the contexts in which social and health care were delivered and resourced in different European States.

**KTE Action:**

The target audience for this training was wide – comprising a range of professional and paid carers that included social assistants, physicians and psychiatrists, clinical and educational psychologists, nurses, educators, social workers, speech therapists, physiotherapists. These individuals clearly have a varied background of experience and qualifications including ‘front line’ carers without qualifications.

The choice of trainees also took into account the context of the partner’s countries. In Romania for example, there were not felt to be robust enough community based supports from which a number of trainees could be identified, the preference being to begin work with hospital based staff who often find themselves needing to provide acute inpatient care to people with intellectual disabilities.

The partners made a conscious decision to allow for training to be developed in a context and structure that was appropriate to local service structures, professional resources available and local logistical issues in bringing groups of individuals together on a regular and time limited basis. Although key materials in terms of themes, content and supporting information was supplied, the delivery of this curriculum was again determined by partners and local educators on the basis of their knowledge and experience of similar training events and the teaching skills and styles of the local expertise involved.

A variety of media and teaching methods were used within the training programme itself and there were also dissemination events, a website with information and downloadable materials.

**KTE use:**

A process of internal evaluation was carried out at the beginning and end of the courses focussing on effectiveness in delivering key concepts and relevance to the individuals and their working context. Evaluation questionnaires focussed specifically on ratings of relevance and change in knowledge, perceptions and attitudes.

Preparation for the course in identifying an individual with ID well known to the individual participant and bearing them in mind during the training programme aimed to enable the issues covered to be directly related to the individual’s own experience and learning needs.

**KTE impact:**

A longer term evaluation of the training courses was carried out at 6 months which aimed to establish an idea of the lasting impact on participants and their expectations for their own future development and support.

Papers describing the project and some of its results were delivered at European conferences and dissemination conferences in Romania, Portugal and Luxembourg targeted at a wider range of professionals from health and social care backgrounds and in addition were able to engage key policy makers, local service providers, government departments, senior officials of special-interest organisations, Higher Education Professors. In addition to improving knowledge and practice of participants therefore, the project had wider impact on the strategies, development and delivery of mental health and other relevant services in the partner countries and influence on services in other European States and possibly the international community.

The external evaluation of the project together with the findings and experience of the partnership group leads to a set of conclusions and recommendations for future initiatives and some concrete proposals following through from this project that complete the knowledge transfer cycle in contributing to the background evidence and data that can inform a continuing and evolving process of the transfer and exchange of knowledge about the mental health needs of people with intellectual disabilities and their carers.
Knowledge-brokers

There is a need for a political stand to make bridging and knowledge transfer key components of any programme in the fields of disability and mental health. A mechanism should be established for the exchange of information; to enable working together to identify good practices and success factors in bridging and knowledge transfer. New notions related to knowledge transfer, such as ‘networks’, ‘knowledge brokering’ and partnerships lack consensus and share a limited understanding about what they mean and how to implement its use in this care sector. There is a need for action for development and improvement at an EU-level by involving the relevant policy makers and stakeholders, including those from the health, education, social and justice sectors, social partners, as well as civil society organizations. (Salvador-Carulla, 2010)


Saini, M. &. (2010). InFormation: A model for knowledge transfer and exchange (KTE).

Following the collation and elaboration of the current knowledge base, the partners in the TRINNODD project worked collaboratively and individually to establish training modules in each country, the aim of the training being to enable those undertaking the training to have a better theoretical understanding and practical approach to supporting people with intellectual disabilities who also have mental health problems. The core content of the training programmes would be based largely around the result of a needs assessment conducted within the first stage of the project.

The assessment aimed to evaluate both the knowledge and the needs of staff in relation to dual diagnosis. An assessment was also made of the perceptions of service users and of their families with regard to the concepts of quality of life and how services affect this.

The methodology chosen included the development and delivery of a survey on staff training needs as well as users’ and families’ quality of life needs. The background, cultural and other work environment-related characteristics of each trainee was analysed at the very beginning of the training programme.

This assessment was carried out in Spain, Romania, Italy, Portugal and Luxembourg. Although no training was planned for Luxembourg, the questionnaire was circulated to a number of women working as an “aide socio familiale” who had completed the TRIADD course some years previously.

A 17-item questionnaire, called TTND (Trinnodd Trainee Needs Definition), was randomly given to around 250 experienced staff members. It was completed and returned by 170 experienced staff members (educators, psychologists, social workers, nurses and others) and by 160 persons with Dual Diagnosis or their family members. They were randomly selected in different settings across the 4 countries participating directly in the project. Staff members were asked to describe the context of their work, the subjects related to DD that could have been useful to them, the principles or practices their team was following and the specific training they had received so far. Families and users were asked to express which topics should be developed by the support team to help them achieve a better quality of life. It is important to note at this point that the Quality of Life concept was ‘new’ in Romania. Support workers showed a lack of motivation to teach families how to take care of people with Dual Diagnosis as they themselves were reported as being dissatisfied with their own lives.

Within the settings of these four countries, the following subjects were identified as a priority for training:

- stress prevention,
- assessment of individual and family quality of life,
- complexity of individual vulnerability,
- environment (family and community),
- different approaches to intellectual disability,
- technical knowledge of Dual Diagnosis,
- effective communication.

These conclusions, which were added to recommendations from the former project TRIADD, to the results drawn from recent research studies brought by research partners (SIRM, AECCR) and to the observations of the external evaluator, were compiled by a small working group within the partnership, on a draft proposal approved in May 2009 by all as the guidelines to develop the new training modules.
In detail the guidelines stated that all partners should consider 4 main innovative dimensions:


**Emotional**
This dimension was concerned with tapping into the trainees own thoughts, feelings and experiences as a means of enabling an empathic and normative approach to understanding mental health. This was addressed in part through:

- **Personal reflection about the trainees own experience of mental health** – what life experiences, knowledge and skills did they bring to this area of work
- **Identifying a person/s with intellectual disability known to have mental health problems and getting to know them as thoroughly as possible** – keeping the individual in mind during the course.

**Technical**
This concerned the factual knowledge, skills and theoretical background to the promotion and maintenance of mental health for trainees and for the people with intellectual disability whom they support:

- **Stress prevention for users and staff**
  This was identified often in the assessment and whilst this may relate significant factors such as workload, pay-scales, hours of working, organisational dysfunction and lack of adequate and appropriate support, this may also reflect the difficulties of working in close proximity to or caring for people with complex problems, who may be highly dependent and / or challenging in their behaviour. Stress among service users will have multiple and complex aetiologies but it is also recognised that stress levels in staff, families and in service users are closely interrelated. It has been shown that reducing stress in carers can be associated with a reduction in problematic behaviours in the individuals they are supporting.

- **Multidisciplinary work is of great importance**
  Many different professionals may be involved in the lives of people with intellectual disabilities and may have varied experience and perceptions of the individual. They also bring a variety of skills to the processes of diagnosis, support and treatment, essential when working with a group in whom diagnosis may be very difficult due to the degree of intellectual impairment and deficits in communication.

- **Detect of ‘early warning signs’**
  Families and Staff should be enabled to detect the early warning signs of psycho-pathological problems. Early detection and seeking of help leads to a greater chance of early intervention and subsequently better outcomes in terms of prognosis.
• **Effective communication between staff members and families**

It is important to distinguish between explaining and understanding. This module did not focus on the communication topic in general since it is too wide; specifically it dealt with effective communication between staff members (e.g. how professionals interpret phenomenological approaches, how different cultural approaches affect interpretation, how to communicate effectively within the staff to reach real outcomes). Good communication with families is promoted to improve their understanding of diagnosis and treatment (the use of drug treatments for example) and to enable professionals to understand better the individual, their life story and their social, cultural and spiritual background, thereby leading to more accurate diagnosis of problems in mental health.

• **Therapeutic relationship:**

This is the relationship that a healthcare professional develops in order to engage with and bring about change in a client. Whilst used most often in the psychotherapeutic context it is also important in other aspects of understanding and improving a person’s physical and mental wellbeing. It involves such concepts as warmth, genuineness, unconditional positive regard. For people with intellectual disabilities, who are frequently stigmatised and isolated through people's reaction to their disability, a therapeutic relationship may require particular effort to made for its development.

• **Pharmacological intervention:**

In addition to providing general information about drugs and drug treatment, the training module should convey a few pharmacological principles useful for daily practice, for the early detection of the unwanted effects and recommendation from guidelines on the use of medication in people with intellectual disabilities. Overall the aim was to empower non-medical staff to ask doctors informed questions on the rationale, risks versus benefits, effectiveness and prognosis of drug treatments. There are many misconceptions about drug treatment, sometimes people associate drugs with severe side-effects and dependency, there is also a widely established polarisation of perceptions with regard to drug versus non-drug interventions, the former being regarded as “bad” and the latter as “good”. These perceptions may then become attributed to the professionals involved in their administration, doctors and psychiatrists perceived as promoting “bad” and “harmful” drug treatments as opposed non-medical practitioners. The training courses aimed to promote a synthesis of treatment approaches to mental health and also to model collaborative and integrated interventions from a range of professionals. Informing and supporting people with intellectual disabilities, their families and carers enables them to be better involved in their treatment and is consistent with modern “recovery based” models of mental health.

• **Challenging Behaviour:**

There is considerable overlap between the concepts of mental health and challenging behaviour. Difficult behaviour is a form of communication and may be a response to, or expression of, trauma, adverse life events, unhappiness or psychotic experiences. Behaviour does not occur in isolation, as well as antecedents and consequences there are biological, environmental, social and cultural factors that need to be taken into account. The experience and labelling of challenging behaviour by supporters and professionals is unreliable, behaviours that are seen as challenging by some are not experienced in the same way by others. Behavioural challenges may therefore require a detailed and multifactorial approach with open communication, integrated understanding and structured assessment from a range of professionals is a challenge.
Methodological
This refers to the way in which the training is delivered and in which the trainees engage with it.

- **Preparatory work of trainees before the training session:**
  Trainees were encouraged to reflect on their awareness, attitude to and experience of mental health issues before the training session. This was to be kept in mind throughout the sessions, informing discussion and normalisation of concepts being presented. It was expected that this link between theory and personal experience would lead to more effective learning and implementation of ideas in day-to-day practice after the course was complete.

- **Case stories:**
  In addition to thinking about their own personal experience, trainees were also asked to identify, think about and bear in mind an individual well known to them who has intellectual disabilities and mental health problems. In the case of the Portuguese training, a collection of case vignettes was put together from contributions by the trainees for all participants to consider.

- **Interactivity during the training session:**
  In the drafting of the training module it was felt important to find a way to promote an interactive approach through teaching methods, case discussion, feedback etc.

- **Involve psychiatrists in the training session:**
  This was one of the recommendations of the previous TRIADD project.

- **Users involvement:**
  Reflecting upon the TRINNODD main goal the partnership agreed to develop strategies to involve users in the training development and delivery.

Quality of life approach
In the field of Intellectual Disability, concepts of healing, cure or recovery need to be understood in the context of pre-existing levels of ability and functioning that are different to the general population. The main focus of therapeutic interventions that has emerged over the last two decades is improving Quality of Life (QoL) which is seen as providing a more positive, person centred and holistic approach than a “traditional” medical one. It surpasses the criteria of normality and structural / functional integrity, suggesting instead value in a treatment based on the person in their own physical and social complexity and not simply on the disorder or symptoms affecting them. Partners were encouraged to bring together the most recent developments on this subject in their training modules including within the conceptual framework, bio-psycho-social models of aetiology, assessment and intervention.

Supporting information from the “evidence base”
During this collaborative and integrative process, all partners add access to a set of PowerPoint slides informed by the current literature concerning quality of life, attitudes toward disability and social inclusion, life events approach and family / environmental factors in pathogenesis and in intervention. Articles by partners (Luis Salvador Carulla (SP), Marco Bertelli and Giampalo la Malfa (IT)) as well several references, documents, articles and .pdf books from the dual diagnosis field were brought together and shared within the partnership. Sources included: The ESTIA centre (UK); TURNING POINT (UK); Royal College of Psychiatrists (UK); British Psychological Society (UK); MHID – Mental Health in Intellectual Disability (EUR); National Association for the Dually Diagnosed (USA); POMONA Project (EU); FEAPS (SP); WORK POSITIVE (UK); NHS (UK); WHO and WPA documentation.
Accreditation

The presentation of training modules in every country underlined the importance of interactivity and involvement of participants in training sessions; the modules brought a connection between different sectors, between theory and practice. The variety of contents delivered had an added value as it was possible to make comparisons between what would work in each country in order to establish a basic standard to develop (core curriculum). The importance of certifying the courses arose during delivery of first training courses; accreditation at a European level would strengthen the development of knowledge in this field and increase transfer of innovation among professionals of different countries (exchange of professionals, online material etc.). Links would be important with other ID organizations, with universities and national and international organisations such as legislators and policy makers. The starting point to this path was to obtain national accreditation: in Spain for example TRINNODD courses had a certification of the regional administration Generalitat de Catalunya- Institut d’Estudis de la Salut.

4. The Use of Knowledge

The TRINNODD partnership developed the first phase of Dual Diagnosis training modules which were subsequently delivered starting with the first one in November 2009 in Lisbon – Portugal and last in March 2010, in Reus – Spain.

The description of these training modules is as follows:

For Portugal – FENACERCI

<table>
<thead>
<tr>
<th>Hours</th>
<th>30</th>
</tr>
</thead>
</table>
| Trainers | Mª Filomena Amaro, Psychiatrist  
Maria Joâo Gonçalves, Psychologist  
Sónia Fontes, Psychologist  
Raúl Melo, Psychologist |
| Trainees | Front Line Staff in Day Care Centres and Residential Units:  
• Social workers  
• Therapists  
• Psychologists  
• Educators  
• Carers |
| Main Topics | • Mental health of professionals  
• Intellectual Disability, Mental Health Problems  
• Dual Diagnosis and Vulnerability factors to develop Mental Health problems  
• Multidisciplinary team intervention regarding DD  
• Stress management support strategies within the teams |
### For Italy - SIRM

<table>
<thead>
<tr>
<th>Hours</th>
<th>20</th>
</tr>
</thead>
</table>
| Trainers | Marco Bertelli, Psychiatrist  
Stefano Lassi, Psychiatrist  
Gianpaolo La Malfa, Psychiatrist  
Ciro Ruggerini, Psychiatrist and Infant Neuropsychiatrist |
| Trainees | Staff in Day Care Centres and Residential Units:  
• Nurses  
• Therapists  
• Psychologists  
• Psychiatrists  
• Educators |
| Main Topics | • Different approaches to intellectual disability  
• Quality of Life  
• Dual diagnosis and Autism  
• Life Events and Transition  
• Stress and vulnerability of people with ID and MH problems  
• Burden on operators  
• Environmental factors - Community and Inclusion  
• Environmental factors - Family in pathogenesis and in intervention |

### For Romania – Foundation UCOS

<table>
<thead>
<tr>
<th>Hours</th>
<th>30</th>
</tr>
</thead>
<tbody>
<tr>
<td>Trainers</td>
<td>Svetlana Popovici, Psychiatrist</td>
</tr>
</tbody>
</table>
| Trainees | • Doctors  
• Psychologists  
• Nurses  
• Carers  
• Psychiatrists |
| Main Topics | • Stress management  
• Quality of life (personal health and patient’s health)  
• Stigma  
• Challenging behaviour  
• Vulnerability  
• Multidisciplinary approach |
For Spain – AEECRM

<table>
<thead>
<tr>
<th>Hours</th>
<th>20</th>
</tr>
</thead>
</table>
| Trainers    | Mencia Ruiz, Psychologist  
|             | Mar Maduell, Psychologist  
|             | Daniel Gallo, Psychologist  
|             | Rafael Martinez, Psychologist  |
| Trainees    | Auxiliary Care Givers |
| Some Topics | • Rehabilitation interventions in ID  
|             | • Role of the mental health carer professional  
|             | • Relationship with the patient  
|             | • Behaviour Problems and DD  
|             | • Basic psychopathology  
|             | • Intervention in special situations  
|             | • Stress and Quality of life |

Although each country and each of the partners developed their own particular emphasis and set of training priorities, based on the analysis of their target audience this was built on a shared understanding and commitment to the whole curriculum and its aims.

In order to confirm that we were targeting the right audience, with the appropriate content relevant to their needs and their work, and in light of the recommendations from the former TRIADD project that further projects should focus on the evaluation procedure, TRINNODD partners designed specific evaluation forms to be carried out:

1. Short term questionnaire (15 item) before and after the course  
2. Satisfaction questionnaire (9 item) after the course  
3. Long term questionnaire (11 open questions) 6 months after the course
As an example, the first questionnaire delivered (Form1) had to be completed in the beginning of the course.

The results, considering all countries were as following:

<table>
<thead>
<tr>
<th>Topic</th>
<th>NOT IMPORTANT</th>
<th>HIGHLY IMPORTANT</th>
<th>DON'T KNOW</th>
</tr>
</thead>
<tbody>
<tr>
<td>BASIC KNOWLEDGE ABOUT INTELLECTUAL DISABILITY AND MENTAL HEALTH</td>
<td>1 2 3 4 5 6 0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>HOW WE DECIDE WHAT IS NORMAL AND WHAT IS ABNORMAL</td>
<td>1 2 14 69 1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>HOW MENTAL HEALTH PROBLEMS CAN START AND DEVELOP IN PEOPLE WITH ID</td>
<td>2 5 25 53 1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>THE KIND OF PSYCHOLOGICAL PROBLEMS THAT PEOPLE WITH ID HAVE</td>
<td>1 6 26 52 0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>HOW TO COMMUNICATE BETTER IN ORDER TO UNDERSTAND PEOPLE’S PROBLEMS</td>
<td>2 3 17 64 0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>THE RANGE OF INTERVENTIONS FOR HELPING PEOPLE WITH ID AND MENTAL HEALTH PROBLEMS</td>
<td>0 0 15 71 1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>PSYCHOLOGICAL TREATMENTS</td>
<td>0 1 11 73 1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>TALKING TREATMENTS (COUNSELLING AND PSYCHOTHERAPY)</td>
<td>2 5 20 58 0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>DRUG TREATMENTS</td>
<td>2 7 29 47 2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>MULTIDISCIPLINARY WORKING AND ROLES</td>
<td>1 4 14 67 0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>EVALUATING QUALITY OF LIFE</td>
<td>0 4 11 69 2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>RELATIONSHIP BETWEEN DUAL DIAGNOSIS AND CHALLENGING BEHAVIOUR</td>
<td>1 3 20 62 0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>ASSESSING AND MANAGING RISK</td>
<td>0 10 16 59 1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>LOOKING AFTER YOUR OWN MENTAL HEALTH</td>
<td>1 2 11 69 4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>MANAGING STRESS</td>
<td>0 3 15 67 1</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 1 – First Evaluation before Training – Form 1 – Global Results in the partnership (n=86)

The trainees attributed a high degree of importance to all topics stated in the form – 87% scoring 5 or 6 to each category.

95% gave scores of 5 or 6 to the categories of BASIC KNOWLEDGE ABOUT INTELLECTUAL DISABILITY AND MENTAL HEALTH, HOW TO COMMUNICATE BETTER IN ORDER TO UNDERSTAND PEOPLE’S PROBLEMS, THE RANGE OF INTERVENTIONS FOR HELPING PEOPLE WITH ID AND MENTAL HEALTH PROBLEMS, RELATIONSHIP BETWEEN DUAL DIAGNOSIS AND CHALLENGING BEHAVIOUR and MANAGING STRESS.

The clarity of the message and of the contents were assured by the fact that each country and partner could adapt and tailor the most appropriate information to their own national context and specific needs as assessed during the first TRINNOODD work package.

A high majority of participants quoted that the course was relevant to their working reality and that it covered most of the expected outcomes. In particular they stated to have gained a better knowledge and evaluation of Quality of Life elements, stress management, communication competences to better understand users and families problems.
Second Cycle

Unexpectedly, the project found itself in a position to run a second cycle of training courses in the partner countries. This provided an opportunity to work through a separate but embedded knowledge transfer cycle involving an analysis of the impact of the first training cycle. Clearly the training had been well received and was seen to be well targeted around trainees’ needs and expectations. The strengths of the project are that it is a flexible, interactive and knowledge-based process. The diversity of the target audiences, the mode of delivery and the emphasis in content between the partner countries was seen also to be a strength, given that this was consistently focussed around a core syllabus and sets of aims and objectives. It became apparent that it would be feasible to develop a core curriculum based upon in the in-project experience, formal and informal evaluations.

A consensus process between all contributors identified the following categories as priorities:

<table>
<thead>
<tr>
<th>order</th>
<th>Topic</th>
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</thead>
<tbody>
<tr>
<td>1.</td>
<td>Mental Health and Behaviour</td>
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<tr>
<td>2.</td>
<td>Quality of Life and its relation to Mental Health</td>
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<tr>
<td>3.</td>
<td>Vulnerability &amp; Resilience</td>
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<tr>
<td>4.</td>
<td>Assessment &amp; Intervention</td>
</tr>
<tr>
<td>5.</td>
<td>Stress Management</td>
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<tr>
<td>6.</td>
<td>Comments on User Involvement</td>
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<tr>
<td>7.</td>
<td>Comments on Sibiu Declaration</td>
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</table>

- The issue of multidisciplinary working would be addressed across all the main topics
- In every course there would be the opportunity to address the topic of user involvement, whether by direct presence of the user during a part of the session, by feedback from participants of comments they obtained from service users before attending the course, involvement of service users in the planning and/or delivery of sessions

*Details about the Core Curriculum can be found in Appendix B.*
5. Evaluating The Impact

Materials and Methods

The evaluation of training needs in participating countries was based on the creation of an appropriate questionnaire. This 17-item tool, called TTND (Trinnodd Trainee Needs Definition), was randomly given to around 170 experienced staff members supporting people with DD in different settings across the 4 European countries (Italy, Portugal, Romania, and Spain). They were asked to describe the context of their work, the subjects related to DD that could have been useful to them, the principles or practices their team were following and the specific training they had received.

A modified version of the TTND was also randomly compiled by or administered to a group of 50 persons with ID and 111 family members.

Considerable divergences emerged between Romania and the other countries, while only minor differences were noticed for Italy, Portugal, and Spain in respect to each other. Four main areas of innovation were identified: emotionality, quality of life, vulnerability, and training methodology. Within these, the following subjects were identified as a priority for training: stress prevention, quality of life assessment, family quality of family life, complexity of individual vulnerability, environment (family and community), different theoretical approaches to intellectual disability.

To assess trainees’ and trainers perception of usefulness and satisfaction towards the courses, further specific instruments were created.

Trainees were asked to complete a short term questionnaire (15 item) before and after the course, a satisfaction questionnaire (9 item) after the course, and a long term questionnaire (11 open questions). Trainers were also asked to complete a 5 item evaluation questionnaire after the course to be included in each partner’ internal evaluation form.

All data were entered in a previously created database and statistically analysed.

To verify between-group differences Student’s T test and Anova post-hoc were used.

Some main differences were also controlled through analysis of variance for non-parametric data (Kruskal Wallis Test). To verify tendency of questionnaire items to group, Jonckheere-Terpstra and cluster analysis were applied.

The same methods of assessment were used for the prolongation phase courses, but not the Jonckheere-Terpstra technique. Another difference is in that of the structure of the long-term questionnaire, with open questions substituted by multiple choice, the latter based on results of the assessment of the previous course.
Results

First Course
Around 85 trainees completed the pre-course form. 58 after-course forms were sent back to SIRM for statistical elaboration.

Mean score differences of attribution of importance before and after the first course were found to be statistically significant for most topics. Also satisfaction scores after the course were very high.

At the long term evaluation (6 months after the course), scores demonstrated that most training issues were still well remembered and had had a significant impact on trainees’ way of thinking, daily practice, and multi-disciplinary involvement. Trainees reported they could improve their own subjective well-being, professional stress management skills, and clients’ QoL. Trainees also highlighted the need for further training, especially on problem behaviours, multi-disciplinary work, and psychiatric disorders.

For technical reason it was not possible to include the Romanian long term results in the international pool, and statistically compare mean score differences together with the ones of other countries. Nevertheless the descriptive results provided by Romania showed a trend in line with the international group.

Second Course
There were 77 participants in the second course. 70 (91%) completed the pre-course and 73 (94.8%) the post-course learning evaluation forms, and 72 (93.5%) the post-course satisfaction forms.

63 (81.8 %) were female and 14 (18.2%) were male. Their mean age was 37.62 (±8.9) years, with a mean work experience of 9.12 (±9.62) years. The mean number of clients/users of trainees’ workplaces was 49.9 (±43.48).

Before the start of the course the mean importance attributed to topics was very high: 5.35 (±0.62) in a range from 1 to 6. However there was a reported improvement after the training (5.56 ±0.46).

The topics that scored lowest for importance at the beginning of the course were: pharmacological (3.75), talking (counseling and psychotherapy) (4.33), and psychological treatments (4.63). The former improved considerably after the training, with a statistical significance (p=0.02) for pharmacology, while psychological treatment scored lower (4.42).

Although there was this partial improvement, pharmacological (4.35), psychological, and talking (counseling and psychotherapy) (4.50) treatments remained the topics that scored lowest after the training.

Beside psychopharmacology, topics with statistically significant score improvement after the course were multidisciplinary working and roles (p=0.001), the kind of psychological problems that people with ID have (p=0.015), and the way mental health problems can start and develop in people with ID (p=0.02).

Only one topic reported a statistically significant score worsening, this was the range of interventions for helping people with ID and mental health problems.

Trainees reported themselves to be very satisfied with the teaching [5.28 (±0.75) in a range from 1 to 6] and rated very high the content and the organisation of the course overall, respectively 3.27 (± 0.28) and 3.73 (± 0.37) in a range from 1 to 4.
6. Conclusion

During the term of the project, a conference was held in Lisbon, organised by the partners from Portugal and in which a range of topics were presented relating to mental health and intellectual disability. A summary of this conference is given in Appendix A.

At the final dissemination conference in Sibiu, Romania, a charter of conclusions was presented and received the endorsement of participants:

SIBIU CHARTER FOR THE MENTAL HEALTH OF PEOPLE WITH INTELLECTUAL DISABILITIES

Facts:
- Disability Policy is primarily a policy of Human Rights
- The prevalence of Mental Health problems is higher in people with ID than the general population.
- Theses Mental Health issues pose a higher risk of segregation and unequal opportunities for this target group, in comparison with non-disabled people.
- There is a greater biological-psychological-social vulnerability in this group of people.

Conclusion:
Mental Health and Disability policy should emphasize prevention and treatment of mental health problems of people with intellectual disabilities in order to improve their quality of life!

Outcomes:
- Inclusive collaboration between general mental health services and general services for people with ID should facilitate a life-long prevention, intervention and after-care for people with intellectual disabilities.
- When indicated, complementary, specialised support should be delivered by multidisciplinary services/teams.

Health Plans
These outcomes should be part of all national strategic (mental) health plans for people with ID including all relevant stakeholder from the fields (including service users and their family carers), based on the United Nations 2006 Declaration on Rights for People with Disability (Article 25)

Availability of health data & statistics
In many European countries data on mental health disorders and problem behaviour are not available in national health reports.

The failure to address mental health problems of people with intellectual disability on a national health policy level may have several adverse consequences:
- Deficits in structures (services) in the health (mental health) system for this population,
- Inadequate provision of specialised professionals,
- Deficits in higher education programmes such that they are unable to assure high standards in training for professionals in mental health and problem behaviour for the population with ID,
- Inadequate research focusing on mental health for people with ID.
Evaluation and Research

There is a great need for Evaluation and Research in the field of Mental Health and ID to improve scientific and evidence-based prevention, treatment and after-care.

In order to realise this, research policy should create a supportive environment for evaluation and research in the field of (mental) health of people with ID, systematic research on treatment effectiveness and in addition to RCT design studies also qualitative, process-based, effectiveness studies.

Staff Training

Attitudes and values:
Training should primarily be understood as a process to empower staff to take responsibility and initiatives in improving the well-being of the people they support rather than being “conditioned” to carry out traditional and non-personalised responses to the needs of the individual.

High quality of services require the best qualified staff

- Staff require training on mental health and intellectual disability issues

This training should contain

- Specific information & knowledge
- Information about framework of Quality of Life
- A basic knowledge of mental health issues
- A basic knowledge of observation and evaluation tools
- Specific skills and attitudes
- Ability for reflective functioning
- Open-mindedness towards for peer-group and individual supervision
- Ability of cooperation in a multidisciplinary environment
- Being open to the exchange of different approaches and expertise
- Being open to the exchange of information and knowledge between different staff qualifications and between different professionals
- Accepting the importance of interaction between practice, theory and research
- Staff needs special support to cope with mental health issues of people with ID and their own vulnerability

Ongoing Processes

- Life-span approach in supporting people with ID in a holistic way
- Lifelong learning approach for staff training concepts
- Lifelong support for professionals, families and users
Future activities

The partners from all European Countries participating in the TRINNODD project expressed the need to undertake more investigation and promotion for mental health and mental health services accessible to persons with an intellectual disability in the future. Possible action points include:

- Development of specific core curricula for different professionals and operators working in nursing / medical / social care and in education
- Promotion of a survey on the inclusion of specific training on DD in academic programmes across European countries
- Initiate collaborations between European NGOs such as ARFIE, Mental Health Europe, EAMHID and EDF (European Disability Forum) to establish, for example, a memorandum with indicators for best practice in continuous staff training as demonstrated by the TRINNODD partnership
- Awareness raising and motivation in the direction of a more structured partnership between practitioners, front line staff and service providers
- Introduction of necessary changes to existing Mental Health systems in order to reduce the incidence of mental health problems in people with intellectual disabilities, and ensure that they receive equality of access to mental health care and benefit from an increased quality of life. First efforts have been made in the Catalan Health Plan and Tuscany Health Plan (see detailed reports by experts on the TRINNODD Website www.trinnodd.eu). Another incentive has been given through the project activity to put mental health issues for people with an intellectual disability as a priority onto the agenda of the future National Health Plan in Luxembourg
- Connection to WHO-Europe Declaration and Action Plan for the Health of Children and Young People with Intellectual Disabilities and their families and activities aimed to promote the relevant priorities and action plans from the declaration in collaboration with other NGOs
- Cooperation within the development of a European Charter on the right to mental health for people with ID (initiated at the Amsterdam conference, discussed at the IASSID Rome conference and a draft to be presented at the 2011 Manchester conference)
- Commitment to new activities in the area of ageing and ID, an area where mental health takes a prominent role. (a new project proposal will be submitted by ARFIE partners on this issue under the next call of the Life Long Learning – Leonardo da Vinci Programme)

An opportunity to undertake the first steps in this direction will be given by the Joint Congress of the European Association for Mental Health in Intellectual Disability & IASSID Challenging Behaviour & Mental Health SIRG to be held in Manchester on 1 - 3 September 2011.
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Intervention


Practice Guidelines and Principles: Assessment, diagnosis, treatment and related support services for persons with intellectual disabilities and problem behaviour: European Association for Mental Health in Intellectual Disability


STRATEGIC


Future role of psychiatrists working with people with learning disability - Faculty of the Psychiatry of Learning Disability Royal College of Psychiatrists, London, January 2011
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EUROPEAN MEETING
MENTAL HEALTH AND INTELLECTUAL DISABILITY
BUILDING BRIDGES BETWEEN THEORY, RESEARCH AND GOOD PRACTICE
26th MAY 2010, Lisbon

Summary and Conclusions

Introduction to the Conference
Raymond Ceccotto and Veronique Lafontaine – ARFIE

This introductory session described the TRINNODD project which had been the initiation for this conference. This is a development of a previous project, TRIADD, and is concerned with identifying the needs of carers of people with intellectual disabilities in understanding, supporting and seeking help for the mental health problems of their clients. Each of the partner organisations, from Portugal, Spain, Italy and Romania have carried out a needs analysis and delivered training to a group of carers. The project has been evaluated throughout, both internally and externally.

Panel 1: Mental Health and Intellectual Disability

Health indicators for people with intellectual disabilities in EC – Rafael Martinez-Leal

New Approaches in mental health for people with intellectual disability – Anton Dosen

Vulnerability factors in people with intellectual disability – Roger Banks

The mental health of older adults with intellectual disabilities – Darragh McCausland

Quality of life and other person-related outcomes in psychiatry of intellectual disability – Marco Bertelli

This session began by highlighting how little we know about people with intellectual disabilities and their health needs. We are aware that this group have a higher prevalence of mental health conditions and potentially greater health needs in general. They are, however, more likely to be discriminated against in not being able to have access to the same health care as the non disabled population. There is a balance that has to be reached between inclusion, and the recognition of individual and particular difference, a balance between equality and individuality. The POMONA project aims to enable more comprehensive and relevant measurement of the health of those with intellectual disabilities.

The shortcomings of diagnostic and classification systems and the lack of clarity in describing the mental health and behaviour problems of people with ID were described, in deciding what is ‘normal’ and what is ‘abnormal’ and recommendations made for developing a more developmental and integrative approach not just to categorising but to enabling mental health.

What is increasingly clear are the inequalities in health suffered by people with ID and their relation to social determinants of health and toxic and / or traumatic environments and events in early life. People with ID are particularly vulnerable to such adverse factors and modern services should be looking at how they can nurture
resilience and a protective environment.

It is important to be aware of course that people’s health and needs change over time and particularly with the ageing process. This is a complex process and may affect people with ID at an earlier age; services and professional need to be prepared to provide more comprehensive and multiple interventions and supports as people with ID grow older.

One underlying principle in the assessment and treatment of mental health problems is that of quality of life. This can be both simple and highly complex, particularly when trying to understand the experience of people with severe intellectual disabilities and poor or absent communication. How do we make judgements about the quality of life of others? Can we assimilate both the subjective and the objective observations and what framework should be used? Quality of life is just a measure in itself but is an important “outcome” measure when considering any form of mental health intervention.

Panel 2: Setting up appropriate services in different European countries

A Flemish model of comprehensive linking of services for people with an intellectual disability and mental health problems – Johan de Groef

National Plan for Mental Health – José Miguel Barros

Mental Health in Primary Health Care – Francisco Gouveia

Mental health integrative care - Community based service – Paula Carvalho / Maria João Domingos

In this session we considered local, national and international perspectives on service development. The importance of a holistic approach and the need to ‘think together’ was emphasised as well as the need to provide both quality and equality. Services at all levels need to be included in the thinking, from primary care, through education and social services to specialist health and mental health provision. Primary care in particular is fundamental to the maintenance of a healthy community through prevention, health promotion, health education and collaboration. Although national policy and strategies are important in providing direction and resources, the most person-centred and effective supports and interventions can come from local communities bringing together primary care, health social and community services to provide services that are built around local needs and the particular strengths within those communities. A model of matrix working may be more effective in responding to the complex and challenging mixture of mental health, psychological, behavioural, physical and social needs rather than simply establishing networks, remembering that “no-one is sick alone”. The message throughout all presentations were about the need for collaboration, working and thinking together yet acknowledging that at the same time it is often a lone or single voice who may be acting as a champion for change.

Panel 3: Promoting examples of good practice in professional training and guidance

Promotion of mental health in individuals with severe intellectual disability: A multidisciplinary experience in support service – Filomena Amaro

Rehabilitation Centre D. Manuel Trindade Slqueiro Dynamics – João Paulo Albuquerque, Ana Amorim, Pedro Amorim

When our patients are different…: André Rocha and Catarina Avillez de Basto

Professional training on dual diagnosis – Experience of two member states – Maria João Gonçalves and Sonia
The training of health and related professionals should be based on the understanding that there is no health without mental health. And health and wellbeing are determined by a multiplicity and complexity of factors. Inclusion and equality cannot be achieved for people with ID without necessary medical and health supports and yet there is a recognition that the usual medical model and assumptions may be inappropriate or ineffective. Adaptation and adjustments to health interventions are essential to be able to ensure that people with ID receive the assessment and treatment that they need. In addition to structural and procedural changes in health care, there also needs to be greater understanding and attitudinal change towards the population of people with ID. One important way of bringing about this change in knowledge and perceptions is to introduce health students at an early stage in their training to people with ID and their families. Within the TRIADD and TRINNOD partnerships in which Portugal has been a partner there is already experience of training modules being tested to address the long life learning needs of social and health professionals with regard to dual diagnosis (mental health problems in people with intellectual disability).

FUTURE PERSPECTIVES

• Individually and collectively it is essential for us all to continue to promote the need for greater understanding of, and more effective service and therapeutic responses to, the mental health needs of people with intellectual disabilities.

• Integration and equality is not about everyone receiving the same, adjustments, adaptations, flexibilities and specialisation are all essential components of health services that can enable greater equality of health outcome for people with ID.

• Fundamental to the health and wellbeing of people with ID is the provision of an informed and skilled workforce to provide support and interventions at all levels. There are important core competences and knowledge that should be shared by all.

• The health of the individual is very much dependent on the health of their social and physical environment; we should not manage the individual's problems in isolation from this.

• Training and education of health professionals should be based firmly around the understanding of the person with ID as an individual. Engagement of people with ID and their families in the training programmes of professionals is essential.

• We need to know much more about the health and wellbeing of people with ID; in financially difficult times it will be hard to advocate for more research and development yet this must continue and should utilise the support of human rights and anti-discrimination legislation.

• It is essential to realise that the population of people with ID is not homogenous and unchanging. There are important demographic changes taking place within this group as well as critical biological, psychological and social factors that are in a state of constant change. We need to plan for tomorrow's population as much as today's.

• Greater emphasis is needed on the social determinants of health, on vulnerability and resilience and the need for early intervention in families and societies to address these.

• Service development and redesign should be focussed on the creation and support of local, community-based and person-centred resources working together across statutory, independent and voluntary sectors.

• Above all, the message is clear that we should not feel that we are alone in our thinking and in our practice. There is a powerful network of people, allies and supporters, organisations, knowledge and ideas throughout our neighbouring states of Europe and one that, through developing communications and technology is increasingly at our fingertips.

Dr Roger Banks
May 2010
Instructions for CORE CURRICULUM delivery

The idea of a core curriculum emerges from the experience of participant countries in the preparation of the training modules in response to the necessity of a basic standard common to every partner and useful for multidisciplinary trainees. Main topics were selected from former project (TRIADD) recommendations, developed and distributed among partners for the courses. The testing of the material showed difficulties in some of the countries as there was a gap between the knowledge level of the trainees and the complexity of the contents. To solve the problem the group agreed on creating five simple slides for each of the main topics in order to later adapt them depending on the audience of the course. Testing the core curriculum brought different problems as there was excessive space for self-interpretations of the slides and differences of contents in the end. In order to avoid misunderstandings with the material each of the slides should be accompanied by a text explaining the definitions and concepts as it is showed in the slides below. Partners can add extra slides-information to the topics depending on trainees' needs.
Dual Diagnosis
Mental Health and Behaviour Problems in People with Intellectual Disabilities

CORE CURRICULUM

MENTAL HEALTH AND BEHAVIOUR PROBLEMS
DUAL DIAGNOSIS

INTELLECTUAL DISABILITY

MENTAL HEALTH & BEHAVIOUR DISORDERS

FACTS

1. High prevalence of Mental Health and Behaviour Disorders in ID.
2. Greater difficulties in assessment and evaluation.
4. Mental health and behaviour disorders undermine the persons’ quality of life.
5. Difficulties in evaluation and treatment lead to greater frustration and stress in carers.
6. Despite the difficulties, mental health and behaviour disorders can be and SHOULD be diagnosed and receive specific treatment.

MENTAL HEALTH DISORDERS IN PEOPLE WITH DUAL DIAGNOSIS

SAME CAUSES

GENETIC PREDISPOSITION

• Prader Willi S ➞ Psychosis
• Downs S. ➞ Depression

LIFE EVENTS

• Death of a close relative
• Job change / Economics problems, etc

SAME DISORDERS

ANXIETY DISORDERS

Panic Disorder, Phobias, TOC, etc.

AFFECTIVE DISORDERS

Depression, Bipolar Disorder, etc

PSYCHOTIC DISORDERS

Schizophrenia, Delusional Disorder, etc

SAME SYMPTOMS

ISOLATION

WEIGHT LOSS

HALLUCINATIONS

ANXIETY

ANHEDONIA

DELUSIONS

INSOMNIA

SADNESS

INHIBITION

PARTICULAR SIGNS AND PRESENTATIONS

✓ Self-injury and hetero-aggression
✓ e.g. In non-verbal patients constant cries can reveal fear
✓ e.g. In non-verbal patients constant hitting of the ears can be a sign of hallucinations
MENTAL HEALTH DISORDERS IN PEOPLE WITH DUAL DIAGNOSIS

DETECT EARLY SIGNS AND SYMPTOMS

- Changes in routines, likes and dislikes
- Sleep and feeding patterns
- Unmotivated important weight changes
- Isolation
- Apathy
- Unmotivated cries, smiles or laughs
- Soliloquium (a person talking to him-herself)
- Externalised aggression
- Self-injury
- Sadness, expansive or inappropriate affect
- Intriguing and/or worrying behaviors
- Etc

OBSERVATION

BEHAVIOUR DISORDERS IN PERSONS WITH DUAL DIAGNOSIS

BEHAVIOUR DISORDERS DEFINITION

PRODUCT OF MENTAL HEALTH DISORDERS AND PHYSICAL CONDITIONS

Different Mental Health Disorders can provoke symptoms that may be confounded with Behaviour Disorders. Disturbing behaviours that are new, unusual, with an abrupt onset must be explored and the possibility of being a product of a mental health disorders have to be considered. Some times disturbing behaviours can be caused by physical conditions that involve pain. Again, a medical screening is needed when sudden unusual behaviour disturbances appear.

BEHAVIOUR DISORDERS

- SELF-INJURY
- MANIPULATION
- DESTRUCTIVE BEHAVIOUR
- AGGRESSIVENESS
- SHOUTING
- OPPOSITIONAL ATTITUDE
- STEREOTYPY
- CRIES
- EXPLICIT SEXUAL CONDUCT
Some genetic syndromes are characterised by well established behavioural patterns that are inherent to these conditions i.e. Prader Willi S. & Hyperfagia. These behaviours are difficult to treat and the strategies used should be different. Note, that many behavioural phenotypes represent positive patterns and can be considered as advantages or talents i.e. puzzle solving, friendly attitudes or ability for calculations.

Inappropriate behaviours that are learnt and used in order to get a goal, although the chances of getting that goal are reduced by the behaviour. These behaviours can be modified using psychological interventions and techniques.
## CONCLUSIONS

1. Mental health problems and behaviour disorders are frequent in people with ID.

2. Same symptoms can be produced by different mental health conditions and can also be manifested by different signs in different patients or in different circumstances.

3. Mental health conditions, behaviour disorders, symptoms and signs collate together in a confusing constellation in persons with Dual Diagnosis. Take into account all the possibilities.

4. Mental health and physical medical conditions, genetic syndromes and non-adaptive behaviours can be the cause of different disturbing behaviours.

5. When sudden, inexplicable, unusual behaviours appear, consider different options before reaching a conclusion.

6. Normally the behaviours and the symptoms are uncontrollable. To complain or to argue with the patient only make things worse. Look for your team support. If you feel overwhelmed try to look for new formation opportunities.

## QUALITY OF LIFE
QoL: A POLYSEMIC CONCEPT

Mass-Media meaning
a universal ideal of high quality of most material and most marketable
areas of life (i.e. objects owned, success in career, money to spend,
social environment, holidays and free-time, physical performances)

objective
a person’s life conditions as they appear to an external observer.
Hetero-evaluation.

Medical meaning
the patient’s perception of his own health status
(aspects of life related to wellbeing and functioning)

subjective
the individual perception of satisfaction with the “being in the world”.
It can be evaluated only through the person’s opinion. Auto-evaluation.

QoL vs SUBJECTIVE WELL-BEING

Subjective well-being concerns itself primarily with
affective states, positive or negative.

QoL implies a broader assessment and although affect-laden, it represents a subjective evaluation of
oneself and one's social and material world. The exploration refers to those areas of life that are applicable to anybody’s life.
**GENERIC QOL VS HR QOL**

**Generic**: subjective modulation in those areas that are applicable to anybody’s life

**Health-Related**: mixture of clinical or dysfunctional aspects, compared to normality

---

**QoL: DIMENSIONS**

- **Importance** attributed by the individual
- **Satisfaction** perceived by the individual
- **Opportunities** available
- **Choices** made by the individual

---

Bertelli M. e Brown I. Quality of Life for PWID. Current Opinion in Psychiatry, 2006; 19:508-513

Brown I. et al., Centre of Public Health, University of Toronto, 1995
THE 9 AREAS OF LIFE OF THE QOL-IP

**BEING**
Who the patient is as a person.

- PHYSICAL
- PSYCHOLOGICAL
- SPIRITUAL

**BELONGING**
Connections with one's environment.

- PHYSICAL
- SOCIAL
- COMMUNITY

**BECOMING**
Achieving personal goals, hopes and aspirations.

- PRACTICAL
- LEISURE
- GROWTH

---

Brown I. et al., Centre of Public Health, University of Toronto, 1995

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QoL: MODE OF ASSESSMENT

- Direct interview  
  *person herself*

- Proxy Questionnaire  
  *other person*

- External Assessor Questionnaire  
  *other person*

---

Bertelli M. e Brown I. Quality of Life for PWID. Current Opinion in Psychiatry, 2006; 19:508-513
VULNERABILITY AND RESILIENCE

**Vulnerability**
Characteristics of the child, the family circle and wider community which might threaten or challenge healthy development.

**Adversity**
Life events or circumstances posing a threat to healthy development.

**Resilience**
Characteristics that enhance normal development under difficult conditions.

**Protective environment**
Factors in the child’s environment acting as buffers to the negative effects of adverse experience.
Well-Being

Poverty (Duration & Depth)

Accumulated exposure across the life-course to a wide range of material & psychosocial hazards (e.g., toxins, uncertainty, adverse life events)

Vulnerability & Resilience

Biological (genetics, early development)
Psychosocial (human capital, social affiliations)
Community (social capital, Health Care)

Vulnerability & Resilience

Biological (genetics, early development)
Psychosocial (human capital, social affiliations)
Community (social capital, Health Care)

<table>
<thead>
<tr>
<th>Biological</th>
<th>Psychological</th>
<th>Social</th>
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<tbody>
<tr>
<td>Brain damage</td>
<td>Self-worth</td>
<td>Living in inappropriate</td>
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<tr>
<td>Not all people with</td>
<td>Society values</td>
<td>environments</td>
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<tr>
<td>intellectual</td>
<td>achievements</td>
<td>People with intellectual</td>
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<tr>
<td>disability have</td>
<td>as high social</td>
<td>disabilities often live</td>
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<tr>
<td>brain damage. For</td>
<td>status,</td>
<td>in accommodation where</td>
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<tr>
<td>those who do, this</td>
<td>independence,</td>
<td>they are isolated from</td>
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<tr>
<td>can cause</td>
<td>employment,</td>
<td>their families &amp; community.</td>
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<td>structural &amp;</td>
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<td>In such settings they may</td>
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<td>psychological</td>
<td>family. People</td>
<td>have little choice &amp;</td>
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<td>changes to the way</td>
<td>with intellectual</td>
<td>control over their lives.</td>
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<td>the brain functions</td>
<td>disability may</td>
<td>Such environments may</td>
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<td>have difficulty</td>
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<td>vulnerability.</td>
<td>attaining these,</td>
<td>too much activity or</td>
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<td>which may affect their</td>
<td>stimulation.</td>
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<td></td>
<td>self esteem.</td>
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<tr>
<td>Sensory Impairments</td>
<td>Self-image</td>
<td>Exposure to adverse life</td>
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<tr>
<td>Sensory impairment</td>
<td>People with</td>
<td>events People with</td>
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<tr>
<td>can create a</td>
<td>intellectual</td>
<td>intellectual disability</td>
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<td>barrier to social</td>
<td>disability may</td>
<td>are more likely to have</td>
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<td>integration &amp; lead</td>
<td>feel they are</td>
<td>been exposed to abuse,</td>
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<td>to disablement and</td>
<td>different to</td>
<td>trauma, rejection,</td>
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<td>problems with self-</td>
<td>other people</td>
<td>harassment &amp; exploitation.</td>
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<td>image.</td>
<td>due to either</td>
<td>They are often unaware of</td>
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<td>may feel inferior</td>
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<td>Genetic conditions</td>
<td>Poor coping</td>
<td>People with intellectual</td>
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<td>People with</td>
<td>mechanisms</td>
<td>disability find it more</td>
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<td>intellectual</td>
<td>People with</td>
<td>difficult to plan ahead,</td>
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<td>disability are at</td>
<td>intellectual</td>
<td>consider the consequences</td>
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<tr>
<td>a significantly</td>
<td>disability may</td>
<td>of their behaviour or</td>
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<td>higher risk of</td>
<td>feel they are</td>
<td>tolerate/manage their</td>
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<td>mental health</td>
<td>different to</td>
<td>frustration &amp; anger. This</td>
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<tr>
<td>problems associated</td>
<td>other people</td>
<td>can result in greater</td>
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<tr>
<td>with a number of</td>
<td>due to either</td>
<td>discrimination by others.</td>
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<tr>
<td>syndromes e.g.</td>
<td>their cognitive</td>
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<tr>
<td>Prader-Willi</td>
<td>or physical</td>
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<tr>
<td>Syndrome, Rett</td>
<td>disabilities or</td>
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<td>Syndrome, William’s</td>
<td>may feel inferior</td>
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<td>Syndrome.</td>
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<td>support of others.</td>
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<td></td>
<td>Poor self-image</td>
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<td>can contribute to</td>
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<td></td>
<td>mental health</td>
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<td>problems.</td>
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</tbody>
</table>

Expectations of others
Low expectations by others of people with intellectual disability can lead to reduced opportunities for participation & the chance to develop skills and confidence.
<table>
<thead>
<tr>
<th>Biological</th>
<th>Psychological</th>
<th>Social</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Medication</strong></td>
<td>Bereavement &amp; loss</td>
<td>Family</td>
</tr>
<tr>
<td>Side effects of psychotropic medication, particularly when the person is receiving two or more, need to be considered, as these can contribute to mental health problems.</td>
<td>People with intellectual disability often do not receive the support they require to cope with these stressors. They may not even be told about what has happened. Loss can include siblings leaving home, staff leaving or other clients moving on.</td>
<td>Some family members can be over-protective, reducing opportunities and leading to over-dependence. Caring for a person with a disability may also put increased pressure on a family leading to increased stress which can affect the family’s relationship with the person.</td>
</tr>
<tr>
<td><strong>Epilepsy</strong></td>
<td>Difficulty expressing emotions</td>
<td>Reduced social networks</td>
</tr>
<tr>
<td>Approximately a third of people with intellectual disability have epilepsy, which for some may be associated with mental health problems. Epilepsy can provoke anxiety in a person, which may lead to them avoiding going out &amp; becoming isolated.</td>
<td>People with intellectual disability often have trouble expressing their inner thoughts &amp; feelings. They find it difficult to put subtle &amp; abstract emotions into words.</td>
<td>People with intellectual disability often have smaller friendship groups. They may lack the skills required to develop relationships &amp; broaden social networks. Others may develop abusive relationships or mix with inappropriate peers in an attempt to fit in.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Biological</th>
<th>Psychological</th>
<th>Social</th>
</tr>
</thead>
<tbody>
<tr>
<td>History &amp; expectation of failing. People with intellectual disability are often not given opportunities to achieve, so they develop low expectations. Frequent failure may lead them to develop leaned helplessness, which can lead to a lack of motivation &amp; poor goal setting.</td>
<td>Economic disadvantage. Financial and related disadvantages common for people with intellectual disability can contribute to the person’s vulnerability to mental health problems.</td>
<td>Transitions Movement between services are often poorly managed. Poor communication between services and bad or no planning adds to the problem. The individual may feel they have little control or influence over what happens to them at this time.</td>
</tr>
<tr>
<td>Dependence on others</td>
<td>The reliance on others by a person with an intellectual disability can lead to overdependence, a lack of self-determination &amp; poor problem solving skills.</td>
<td>Discrimination Discrimination by the wider society can leave people with intellectual disability stigmatised and impact on their self-esteem and self-image.</td>
</tr>
<tr>
<td>Legal disadvantage</td>
<td>People with intellectual disability may not be aware of their rights &amp; have to rely on the support of others to be advocates for their needs.</td>
<td></td>
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</tbody>
</table>
• So – if we know what we know about vulnerability (and adversity)

what can we do to nurture resilience (and a protective environment?)
Assessment is the process of collecting and evaluating relevant information about the person, the causes and level of ID, the psychological functioning, the development, the psychological characteristics, the physical health, the social, interpersonal and physical environment, and the behavioral pattern.

### Diagnosis → Intervention

<table>
<thead>
<tr>
<th>Signs and Symptoms</th>
<th>The Person</th>
<th>Assessment of the Environment</th>
</tr>
</thead>
<tbody>
<tr>
<td>✓ Historical and current clinical records</td>
<td>✓ Biological Characteristics</td>
<td>✓ Physical environment</td>
</tr>
<tr>
<td>✓ Interview with person</td>
<td>✓ Psychosocial aspects</td>
<td>✓ Significance of the person for the environment</td>
</tr>
<tr>
<td>✓ Information from caregivers (professionals and families)</td>
<td>✓ Physical disorders</td>
<td>✓ Transitional events (daily centre, residential or family)</td>
</tr>
<tr>
<td>✓ Direct behaviour observation</td>
<td>✓ Psychiatric disorders</td>
<td>✓ Pedagogical problems</td>
</tr>
<tr>
<td>✓ Recognise potential symptoms of mental or physical illness</td>
<td>✓ Functional problems</td>
<td>✓ Social and religious aspects</td>
</tr>
<tr>
<td>✓ Formal and standardised procedures</td>
<td>✓ Communication (skills)</td>
<td>✓ Risk factors</td>
</tr>
<tr>
<td>✓ The impact of life events and transition</td>
<td>✓ Inclusion</td>
<td>✓ Cultural aspects</td>
</tr>
<tr>
<td></td>
<td>✓ Stigma</td>
<td></td>
</tr>
</tbody>
</table>
DIFFICULTIES WITH THE DIAGNOSTIC PROCESS IN ID

What the persons say they are experiencing
- Difficulties in communication skills or language impairment
- Even in verbally competent, auditory hallucinations are the only first-rank symptom that can be detected

What others say about them and how they are seen to behave
- A confounding factor is the belief that such problems are inevitable and unchangeable. This means that help is not sought.
- 'Diagnostic overshadowing' whereby someone's general mental state or behaviour is attributed to the fact that he or she has an intellectual disability.

History of complaint
- The development, for example, of maladaptive behaviours, increasing withdrawal, or changes in a person's state of general well-being may be a marker for a possible mental health problem (baseline exaggeration).
- Establishing a baseline and recording changes are central to the diagnostic process

The presentation of symptoms

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COMPLEXITY OF PHENOMENOLOGY OF PSYCHIATRIC DISORDERS IN ID

- Level of cognitive ('intellectual distortion'), communicative, physical and social functioning
- Level of development ('developmental appropriateness')
- Interpersonal, cultural and environmental influences ('psychosocial masking')
- 'ID overshadowing'
  - Differentiate between psychiatric symptoms and signs and symptoms of underlying brain damage
- Atypical or masked presentation
  - Aggression, screaming, maladaptive behaviours, etc.
- Neuro-vegetative vulnerability
  - Somatic complaints, changes in circadian rhythm, NV dystonias
- 'Cognitive disintegration'
  - Coping impairment and lower threshold

---

INTERVENTION

- Person-centred context
- Respect of the person’s rights
- Multidisciplinary team
- Early intervention when signs are present
- Partnership with families and other carers
- Detailed information concerning the nature and outcome of previous interventions
- Detailed information concerning the nature and outcome of next interventions
- Psychotherapeutic and pharmacotherapeutic interventions delivered in combination with other interventions
- Proactive strategies address the goodness of fit between the person and their environment
- Communication intervention (increasing and teaching ways of communication)
WHEN TO CONSIDER MEDICATION

Risk/ harm/ distress to self/ others/ property
Failure of other interventions
Success of medicinal intervention before
Underlying mental disorders/ anxiety/ ASD/ ADHD etc.
As an adjunct to other measures
Person/ carer choice
Severe consequences of the behaviour

KEY PROCESSES ASSOCIATED WITH USING MEDICATION TO MANAGE PROBLEM BEHAVIOURS IN ADULTS WITH IDD
**BPS Model**

- Biological and medical factors
- Psychological factors
- Environmental factors
- Developmental factors
- Psychiatric Disorders

**Psychological Here and Now**
- Thoughts
- Feelings
- Motivation

**Environment and social Here and Now**
- Sensations

**Condition**
- Instigating
- Processing
- Maintaining

**Mental Health**

---

**Comprehensive Model**

**The Person**
(biological and psychosocial factors, and medical, functional and psychiatric problems)

**Interaction**
(behaviour)

**The Environment**
(material, personal, social, pedagogical and cultural factors, system characteristics and significance of the involved person)

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H-ID Practice Guidelines and Principles – Assessment, Diagnosis, Treatment, and Related Support Services for Persons with Intellectual Disabilities and Problem Behaviour
RBC – A strategy for rehabilitation equalization of opportunities, poverty reduction and social inclusion of people with disabilities. Joint position paper 2004

RBC

CBR MATRIX

<table>
<thead>
<tr>
<th>HEALTH</th>
<th>EDUCATION</th>
<th>LIVELIHOOD</th>
<th>SOCIAL</th>
<th>EMPOWERMENT</th>
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<tbody>
<tr>
<td>PROMOTION</td>
<td>EARLY CHILDHOOD</td>
<td>SKILLS</td>
<td>RELATIONSHIPS</td>
<td>COMMUNICATION</td>
</tr>
<tr>
<td>PREVENTION</td>
<td>PRIMARY</td>
<td>DEVELOPMENT</td>
<td>MARRIAGE &amp; FAMILY</td>
<td>SOCIAL MOBILIZATION</td>
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<tr>
<td>MEDICAL CARE</td>
<td>SECONDARY &amp; HIGHER</td>
<td>FINANCIAL</td>
<td>MOBILITY</td>
<td>POLITICAL PARTICIPATION</td>
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<tr>
<td>REHABILITATION</td>
<td>NON-FORMAL</td>
<td>SERVICES</td>
<td>CULTURE &amp; ARTS</td>
<td>SELF-HELP GROUPS</td>
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<tr>
<td>ASSISTIVE DEVICES</td>
<td>LIFELONG LEARNING</td>
<td>EMPLOYMENT</td>
<td>RECREATION</td>
<td>DISABLED PEOPLE'S ORGANIZATIONS</td>
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<td>PROTECTION</td>
<td>LEISURE &amp; SPORTS</td>
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<td>ACCESS TO JUSTICE</td>
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STRESS MANAGEMENT
STRESS MANAGEMENT

- WHAT IS STRESS?
- HOW CAN WE PREVENT STRESS?
- HOW CAN WE TREAT STRESS?

STRESS

A dynamic response process to an environmental change aimed at reaching a balance between the challenges posed and the available resources of the individual to cope with it.
THE STRESS CURVE

- Performance
- Fatigue
- Extenuation
- Collapse
- Healthy Tension

Activation

TYPES OF STRESS

Environmental challenge:
LIFE EVENTS (Hassles and Hazards) vs TRAUMA

Individual’s response
PHYSICAL versus PSYCHOLOGICAL

Type of response:
EUSTRESS versus DISTRESS

Duration:
ACUTE versus CHRONIC
Psychological Distress

A condition or feeling experienced when a person perceives that demands exceed the personal and social resources the individual is able to mobilise

(Lazarus, 1999)

**PSYCHOLOGICAL DISTRESS**

**NEATIVE EMOTIONS**

Stress Vulnerability

MENTAL DISORDERS
- Depression
- Anxiety
- Adjustment disorders
- Other stress related disorders

PERSONALITY
- Neuroticism
- Introversion
Promoting Mental Health in Intellectual Disability:

Building bridges between theory, research and good practice

Elisabeth Zeilinger & Rita Matolcsi

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.1

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.\(^2\)

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 (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).\(^3\)

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3. 'Mental Retardation' or 'Intellectual Disability': Time for a Conceptual Change. Luis Salvador-Carulla, Marco Bertelli. Psychopathology 2008;41:10-16
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.¹

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)
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.\textsuperscript{4} \textit{(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. \textit{(Germain Weber)}

\section*{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\textsuperscript{5} 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.\textsuperscript{6}

Dosen, Gardner, Griffiths, King and Lapointe\textsuperscript{4} 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


specialized prevention and intervention methods and could be a 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)\(^7\), the Disability Creation Process (DCP)\(^8\), the system of the American Association on Mental Retardation (AAMR)\(^9\) and the Supports Intensity Scale (SIS)\(^10\), 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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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 were 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\(^\text{11}\). 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.\(^\text{12}\) 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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\(^\text{12}\) 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
type 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 a Plan of Action and assure a commitment for monitoring and evaluating (to avoid that it remains on a paper work level)

Further 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
- as an example of good practice in training matters on this subject we could mention the so called “TRINNODD”-project (TRansfer of INNOvation on Dual Diagnosis) in the framework of the Life Long Learning Programme (see under www.trinnodd.eu)

**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.
ARFIE est un réseau européen de partenaires actifs dans la formation, la recherche et les services de qualité pour personnes avec un handicap

ARFIE is a European network of partners active in training, research and quality service provision for people with a disability