

CHAPTER II

THE **NEEDS** OF STAFF AND SERVICES

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At the beginning of the project, front-line staff members from Belgium, France, Italy, Luxembourg and the United Kingdom filled in detailed questionnaires about the people they cared for on a daily basis who, for various reasons, were diagnosed or identified as having Dual Diagnosis – forty nine clients in total from five different countries.

The responses given constitute a revealing and valuable source of information which can be analysed from a number of different perspectives. The main focus here is on two aspects:

1. The major problems caused by Dual Diagnosis to all concerned, and the preferred solutions as expressed by the staff
2. Training – what staff had received in the past and what they felt they still needed.

2.1. THE MAJOR CHALLENGES OF DUAL DIAGNOSIS (SUMMARY OF ALL QUESTIONNAIRES)

The most difficult problems from the point of view of the service – as expressed by staff:

Behavioural: aggression – verbal and physical, unpredictability, overreactions, clients need constant attention, bizarre behaviour not understood or appreciated by others, frequent challenges to authority (but often needing approval), will not fit into group schedule and activities.

Communication problems, lack of motivation, withdrawal and anti-social behaviour. DD and all its possible behavioural manifestations (self-injury, depression, aggression, withdrawal) - all added up to a drain on staff and resources.

Staff wanted to help and to keep things positive for everyone but said themselves that they lacked the necessary training to cope.

Difficult co-operation with psychiatric services, who only intervened in times of acute crisis. Dual Diagnosis added to their already heavy burden because these clients required co-operation with other services.

2.2. FOR THE INDIVIDUAL'S IMMEDIATE ENVIRONMENT

Behaviour created great tension and anxiety in the group, undermined trust, created conflicts; it was difficult to integrate the person with DD and this in turn aggravated their feelings of

rejection and isolation. The person with DD could also be very unfocused and have difficulty recognising limits. There was sometimes alcohol abuse, stealing, sudden and unexplained screams or laughter. They could be frightening, show unpredictable extremes and sexually inappropriate behaviour.

2.3. FOR THE FAMILY

Many staff said their service users had little or no contact with the family, which in most cases exacerbated the psychological problems; one or two staff members mentioned the hiding or disowning by the family of their child with dual diagnosis.

The majority of users had extremely difficult if not traumatic family circumstances where parents themselves had problems such as depression, illness and alcoholism. Some were physically/sexually abused and also had siblings with similar problems.

Over-protection was also mentioned a few times. Some support workers knew nothing about the family circumstances, since written records were patchy or non-existent. A large number of staff members found it difficult to communicate with those families who were interested in the real state of their son/daughter – there was a distinct lack of communication and understanding on many levels.

2.4. FOR THE INDIVIDUAL HIM/HERSELF

The majority of the individuals with Dual Diagnosis seemed to be going through nothing less than mental torment – to differing degrees and in various ways, but torment nonetheless. They had 'no inner peace' were anxious, depressed, self-injuring, frightened, confused, angry and frustrated and often at a loss as to how to get out of that state. The picture was the same in every country - this client group was enduring very real mental suffering which seemed to be worsened (and to some extent probably caused by) the communication and understanding difficulties inherent to the developmental disability.

2.5. SOLUTIONS – ACCORDING TO THE STAFF SURVEYED

What would support workers like to do, given the specific problems they were faced with?

Interestingly, the majority of support workers filling this in did not consider the wider context of service provision but focused specifically on the individuals in their care. Many spoke of wishing to understand the person better, wishing they had more time to devote specifically to that person, to be able to reassure them, give them more confidence, trust and hope, help them integrate better into the group and be accepted. Many staff members were frustrated that they felt unable to help end the misery. In this vein quite a few mentioned the need for

quiet and a place in the centre or service where one carer could better deal with the client with DD on a one-to-one basis, but this did not seem to be on offer in most services.

A number also called for better team co-operation and more support from supervisors in order to allow more individual attention. The staff in all countries surveyed felt over-stretched and under-valued. Whenever there was mention of mental illness in their clients they didn't feel as though they were taken seriously, and they didn't know to whom they could turn for support. Outside support seemed to be offered in times of acute crisis rather than be systematic and on-going (which might have helped avoid the acute crises).

Regular and systematic co-operation with the psychiatric and psycho-therapeutic services was therefore specifically requested. The Italian questionnaire report summed it up by quoting a support worker as saying: 'We need to develop a shared language: On the one hand, when I report a case to a psychiatrist I do not know which elements are central to his work, on the other hand, the psychiatrist tends to underestimate a number of elements that I know the importance of.'

A number cited intensive individual therapy (for the client) as necessary, not just drug intervention. The great majority of clients in this survey were taking neuroleptics and anti-depressants long term.

2.6. TRAINING

Many support workers also referred to their need for **training and better understanding of this condition**, because they currently had to rely on common sense, and this clearly wasn't enough.

Previous training:

Of the forty one support workers filling in these questionnaires, only seven had received any training on the issue of mental health and mental disability, and two specifically on the issue of Dual Diagnosis.

The subjects requested for further training were:

- Basic training on Dual Diagnosis with specific case studies and real solutions – not in clinical terms with medical terminology
- Theoretical background and explanation to these problems
- How to recognise pathological behaviour and what to do: what are the boundaries between psychopathological behaviour and disability?
- Challenging behaviour & aggression – how to react and deal with it in a residential setting?

- Specific therapeutic approaches
- Basic psychology and counselling skills
- Management skills and organising the service
- How to collaborate better with psychiatric services – develop a shared language and avoid jargon, sharing the work load
- Medication – an explanation about the drugs and their effects
- Health and dietary needs
- Communication with families, also about finances and relationship problems
- Staff motivation
- Communication tools between support worker and client
- How to promote integration into a group of workers (and manage a group)
- Training on Borderline syndrome.

2.7. WEB SITE AND KNOWLEDGE OF INTERNET AND E-MAIL

Only thirteen of the forty one respondents said that they had ever used internet or e-mail. It was clear from talking to services, staff and analysing their questionnaires that three key problems stood in the way of a tele-training approach:

There was a distinct lack of IT culture in the services, limited or no access to computers, and relatively little experience of using internet or e-mail.

There was also scepticism about the usefulness of this – a number specifically requested face-to face courses, saying that computers required too much time and discipline.

Since we had limited scope to turn this situation around by providing computers and training before devising the courses, we opted for a compromise solution of offering information on the web site before the courses and the option of discussing cases online with an expert. The web site also serves as a documentation centre with resources specially chosen for their 'accessibility'.