MENTAL HEALTH IN MENTAL RETARDATION
CONTENTS

• Foreword
• Preface
• Introduction
• Aetiology of mental retardation
• Children and young people with mental retardation
• Pervasive developmental disorder (PDD)
• Adults with mental retardation and mental disorders
• Challenging behaviours (behaviour disorders)
• Epilepsy
• Mental health service
• Families and carers
• Offenders with mental retardation
• Prevention
• Legal and ethical issues
• Sexuality and people with mental retardation
• Selective reading list
• International organisations
FOREWORD

We have at present 50 scientific sections in the World Psychiatric Association representing all specialities in psychiatry and its allied branches. One of the main objectives of creating sections in WPA is to collect and disseminate information concerning scientific activities within special fields of psychiatry and mental health, organisations of scientific meetings on topics of interest to the sections and development of educational materials.

The production of "Mental Health in Mental Retardation": The ABC for Mental Health, Primary Care and Other Professionals, by Nick Bouras, Geraldine Holt, Ken Day and Anton Dosen should be a landmark for active sections within the WPA, a spotlight, and an example for sections to propagate for the objectives of the WPA. We find that this booklet satisfies all criteria for the objectives of the WPA, namely to increase knowledge and skills necessary for work in the field of mental health and in the care for the mentally ill. Also to improve the care for the mentally ill, prevent mental disorders, promote mental health, preserve the rights of the mentally ill, and promote ethical standards and parity in the provision of care of the mentally ill.

I feel the section of Mental Retardation has succeeded and excelled the purpose of sections of the WPA. It is particularly difficult to write on Mental Retardation due to its interdisciplinary nature and its diversity: developmental medicine, neuropsychology, education, psychology, vocational training, anthropology, sociology, genetics, etc. This "ABC" keeps clinicians up to date in this wide ranging and rapidly changing information environment.

Association the scope of Mental Retardation extends far beyond medical care, the authors succeeded to include a wider scientific, educational and legal literature having relevance to this important topic.

This booklet is a friendly, concise, state of the art of Mental Health in Mental Retardation and recommended for all those working on this field. I have full confidence that the section of Mental Retardation is able to make this booklet the basis for one of the best educational programs organised by the WPA.

Ahmed Okasha

Secretary of Sections – WPA

Chairman of Ethics Committee - WPA
PREFACE

The principles of care for people with mental retardation have undergone radical changes over recent years. The recognition of their right to live as normal a life as possible, the closure of long stay institutions, the development of community based facilities, the influence of families in the direction of services and the self advocacy movement have been some of the main issues that have affected the care of people with mental retardation in the USA, UK, Europe, Australia and Canada. Several imaginative support schemes have emerged based on a holistic approach placing increasing emphasis on consumer choice, satisfaction and outcomes.

Mental Health has always been an important factor for people with mental retardation. The provision of mental health services for people with mental retardation has received new impetus from the current ideology and philosophy of care. We have witnessed, over the recent years, the emergence of advances in aetiology, diagnosis, treatment and models of service for people having both conditions of mental retardation and mental health problems (dual diagnosis). People with mental retardation have become more visible in the community and psychiatrists, psychologists, and other professional or even primary care providers may attend to their mental health needs.

In some parts of the World, such as the UK, there are psychiatrists and psychologists specialising in the mental health problems of people with mental retardation. In many countries, however, this is not the case and people with mental retardation and mental disorders may be looked after by general psychiatrists, paediatricians and other professionals without special knowledge of their problems.

This short publication of the Section of Mental Retardation of the World Psychiatric Association aims to offer some basic guidelines on the mental health needs for people with mental retardation. Both children and adults are covered. There is a description of the necessary components of the required mental health services for people with mental retardation. A selective reading list is offered at the end together with the addresses of some organisations specialising in people with mental retardation and mental health problems.
INTRODUCTION

What is Mental Retardation?

In each country approximately 1% of the population have mental retardation. Mental Retardation is a disability, which starts before adulthood, and has a lasting effect on development producing:

Reduced ability to cope independently (impaired social functioning) due to

Reduced ability to understand new information and to learn new skills (impaired intelligence)

The essential features of mental retardation are a significantly sub-average general intellectual function, accompanied by significant deficits in social functioning in areas such as social skills, communication and in addition difficulties in attaining personal independence and social responsibility. The onset of mental retardation must be before the age of 18. Traditionally, intellectual functioning has been measured by IQ tests and a significantly sub-average intellectual functioning was defined as an IQ of 70 or below. However IQ tests are now treated with some flexibility that might permit the exclusion from the diagnosis of mental retardation of some people with IQ's lower than 70. This is the case if it is felt that there are no significant deficits in adaptive function (the person's effectiveness in areas such as social skills, communication, daily living skills, etc) Mental retardation can be further broken down into borderline, mild, moderate, severe and profound according to IQ. The IQ level gives an approximate guide to the individual's general level of functioning.

Borderline / Mild Mental Retardation

They represent about 80% of people with mental retardation and their appearance is usually unremarkable and any sensory or motor deficits are slight. In adult life most of these people are never diagnosed. Most of these people can live independently in ordinary surroundings, although they may need help with housing and employment or when under some unusual stress.

Moderate Mental Retardation

People in this group account for about 12% of the learning disabled population. Most of them can talk or at least learn to communicate and they take3 care of themselves with some supervision. As adults they can usually undertake simple or routine work and find their way about.

Severe Mental Retardation

This group accounts for about 7% of the learning disabled population. In pre school years their development is usually greatly slowed. Eventually they may acquire some skills to look after themselves although under close supervision. They may also be able to communicate in a simple way. Association adults they can undertake simple tasks and engage in limited social activities.

Profound Mental Retardation

People in this group account for less than 1% of the learning disabled group. Few of them learn to care for themselves although some eventually acquire some simple speech and social behaviour.
Associated problems

Mental retardation may be accompanied or complicated by motor or sensory deficits, behavioural problems, epilepsy and mental illness.

Are there any other terms used instead of mental retardation?

There are a variety of terms in use, past and present, and internationally which reflect the different disciplines and professions involved in this area - each with its own terminology. Mental retardation is used in the International Classification Systems of DSM IV and ICD 10 and is a medical term. Mental handicap is also a medical term and was in use in the UK but currently has been replaced by a more "neutral" term "learning disabilities". Other terms used in the UK are mental impairment as a legal term and learning difficulties as an educational term. In the USA, Canada and Australia the term developmental / intellectual disabilities is also used.

What conditions are excluded from mental retardation?

Educationally disadvantaged people, brain injury in adulthood, progressive neurological conditions in adulthood, physical disability alone and long term mental illness alone that might be responsible for decline of intellectual ability.
AETIOLOGY OF MENTAL RETARDATION

What are the causes of mental retardation?

The causes of mental retardation can be divided into genetic and environmental, although these categories may overlap.

Genetic causes originate prior to conception or during the very early development of the foetus. Environmental causes include those that effect the developing foetus or those that occur in the perinatal, neonatal or childhood period.

Why is it important that we should know the causes of mental retardation?

It is important for a number of reasons such as:

1. the need for the parents, carers and individuals to understand why mental retardation has occurred
2. the individual and family's basic right to know
3. relief from uncertainty regarding the cause of the disabilities
4. relief from the guilt that family and/or social factors were the cause of the mental retardation or developmental or behavioural disturbance
5. facilitation of grief resolution
6. focusing towards the future
7. instigation of interventions relevant to strengths and needs
8. potential for identifying with and belonging to a support group
9. essential genetic counselling where appropriate for the entire extended family
10. risks for other family members of the condition re-occurring in their offspring
11. possible treatment of specific conditions
12. identification of complications of the disorder understanding of how the disorder may develop over time

Are there common syndromes associated with mental retardation?

The interest in specific syndromes in mental retardation has increased in recent years as it is recognised that, apart from similarities in physical features, there are identifiable behaviours that occur more commonly in certain syndromes.

Examples of these are:

- Down syndrome
- Fragile-X syndrome
- Prader-Willi syndrome
- Lesch-Nyhan syndrome
- Tuberous sclerosis

What are the behavioural phenotypes?
These are repertoires of maladaptive and adaptive behaviours characteristically associated with specific genetic conditions causing mental retardation. Examples include: Down, Fragile-X, and Prader-Willi syndromes.

**What are the characteristics of Down Syndrome?**

Down syndrome is one of the more common chromosomal anomalies associated with mental retardation. The overall incidence is approximately 1 in 700 live births, although a further 50% result in a spontaneous abortion and 20% are still born. Incidence increases with maternal age so at 20 years of age a mother has a 1 in 1,500 chance of delivering a child with Down syndrome. This goes up to a 1 in 50 chance at 43 years of age. Prenatal screening and diagnosis is now possible.

In Down syndrome 95% of cases are due to an extra chromosome 21 (trisomy 21) while 4% of cases are as a result of a translocation and a further 1% is due to mosaicism.

People with Down syndrome have a characteristic appearance with up-slanting eyes, Brushfield spots (speckles in the iris) a small nose and rather flat face. The infant might be hypotonic and have low set ears. A Simian crease (single palmar crease) is present in 50% of those affected with the syndrome. People with Down syndrome are also at risk from congenital heart abnormalities, cataracts, epilepsy, thyroid disorder and leukaemia.

People with Down syndrome have an associated mental retardation and have an increased risk of developing dementia later in life. Depression also occurs relatively frequently with symptoms of anorexia, mutism and decline in cognitive abilities. The differential diagnosis between depression and the beginning of dementia in people with Down syndrome can be very difficult.

**What are the characteristics of the Fragile X-syndrome?**

This occurs when there is an abnormal area on one of the X-chromosomes. Men and women can be affected, although more frequently females are carriers and pass the abnormal chromosome onto their male offspring. It is possible for the diagnosis to be made in pregnancy, and carrier women can also be detected.

The incidence of Fragile-X syndrome is probably 1 in 1000, with 5% of males having a severe mental retardation, but 20% of males are unaffected. It should be noted that the syndrome affects 30% of carrier females.

The physical features of the Fragile-X syndrome are quite variable and cannot be used to make a diagnosis. People with it have lax joints, a long face and large ears, large testicles, cardiac abnormalities and a large head with a long nose. A number of behaviours are associated with Fragile-X syndrome including autistic type behaviours and hyperactivity. People with Fragile-X have specific cognitive deficits and speech abnormalities often in expressing language. Anxiety, hyperactivity, depression, maladaptive behaviours and rapid cycling disorder have also been described.

**What are the characteristics of the Prader-Willi syndrome?**

Prader-Willi syndrome is due to loss of paternal chromosome 15 material causing mental retardation, and physical anomalies associated with insatiable appetite, gross overeating, obesity,
pica, skin-picking, irritability and stubbornness. People with this condition often show angry, aggressive, challenging behaviours if their food-seeking behaviours are thwarted and have personality difficulties, partially due to sensitivity about their physical appearance. Depression and cyclical mood disorder have been described.

**What are the characteristics of the Lesch-Nyhan syndrome?**

Lesch-Nyhan syndrome is an X-linked recessive disorder of purine metabolism that has an incidence of 1:380,000 births. The features are microcephaly, mental retardation, choreoathetosis, spasticity, seizures, hyperuricaemia, gouty arthritis and severe compulsive self-injurious behaviour including biting of fingers, lips and other oral structures. Neurochemical abnormalities have been identified and include significant functional reductions in dopamine in the nigrostriatal mesolimbic tracts.

**What are the characteristics of Tuberous Sclerosis?**

Tuberous sclerosis is a hereditary neurocutaneous syndrome with a prevalence of at least 1:7,000 births. Calcified gliotic tumours develop in cortical regions in addition to malformations of the skin. Approximately two thirds of affected persons have mental retardation, 70-100% have epileptic seizures. Behavioural problems are common and psychotic disorders have been described.
CHILDREN AND YOUNG PEOPLE WITH MENTAL RETARDATION

How can a child who has mental retardation be affected?

The presence of mental retardation put a child at risk of being more:

- dependent on others for help in acquiring basic skills
- prone to physical difficulties
- prone to mental and behavioural disturbance
- prone to social stigmatisation and its consequences

Are there implications for a family who has a child with mental retardation?

The family with a child with mental retardation is put at risk of:

- psychological difficulties in siblings and parents
- marital disharmony

What are the needs of young people with mental retardation?

Young people who have mental retardation have multiple needs:

- those relating to their mental retardation - medical, cognitive and behavioural
- those relating to their age - educational, emotional and social
- those relating to the impact of their mental retardation on the family

How can services meet the needs of young people with mental retardation?

Children with mental retardation can be viewed as children at risk - from biological, psychological and social factors all of which interact and need intervention and support in all these areas.

A multitude of services and professionals is required to address the individual's needs adequately; to promote as normal development as possible and to prevent the development of secondary handicaps to which these children are more prone.

Different services predominate in their contribution at different ages. Paediatricians and Child Development Teams in the pre-school period, and specialist psychiatric and psychological services for young people throughout childhood and adolescence.

What is the prevalence of mental & behavioural problems in children with mental retardation?

There is an increased prevalence of mental and behavioural disturbance in children with mental retardation compared with their non-mentally retarded peers. This is due to a combination of biological, psychological and social factors. The following percentages of children have been found to have an identifiable psychiatric disorder:

- 7% of children in the general population
- 12% of children with a physical disorder or disability
- 33% of children with a brain dysfunction
- 50% of children with severe mental retardation
What are the causes of mental & behavioural problems in young people with mental retardation?

There are many causes of mental and behavioural problems in young people with mental retardation. Usually several of these will be responsible for the difficulties faced by any one child. These include:

- **Constitutional:**
  
  As with any young person the individual's temperament, which is itself strongly genetically determined, will contribute substantially towards how the child reacts to experiences, and thus the nature and intensity of mental or behavioural disturbance. Also, the presence of a specific genetic cause (e.g. Fragile X syndrome, Prader-Willi syndrome) will determine what developmental and behavioural challenges are likely to be encountered.

- **Medical:**
  
  Behavioural disturbance may be the consequence of a medical condition, for example diabetes or epilepsy. It may also be a sign of physical discomfort in a child unable to communicate effectively, for example in the presence of severe pain due to appendicitis or a fractured bone. Self-injury in the form of hitting the side of the head is a well-recognised presentation of middle ear infection (otitis media). Epilepsy can present as disturbed behaviour even when full consciousness is maintained. Psychiatric disorder will often present with behavioural problems and although serious psychiatric conditions such as schizophrenia and manic-depression are rare in children with mental retardation, they occur more often in this group than in children with average intellectual functioning. Brain damage may be a cause of both the mental retardation and the behavioural disturbance. Medication can be a contributor as well.

- **Developmental:**
  
  Behaviour may be appropriate for the developmental stage reached. It is often the discrepancy between the young person's progress in physical size, strength and motor skills, and their limited intellectual, social and emotional capacities which creates problems.

- **Cognitive:**
  
  It is not things themselves which disturb us but the view we take of them. Thus the reaction of others to the individual's disabilities is crucial but so is the reaction of the individual with mental retardation to their perception of the stigma associated with having disability and their perceptions of other's reactions. This explains why personal counselling and public education must always go hand in hand.

- **Familial:**
  
  Mental or behavioural disturbance in a young person with mental retardation may be an understandable reaction to family tensions, psychopathology or expressed emotion. This may take the form of a reaction to persisting familial grief or chronic sorrow, or to parental anxieties regarding the past, present or future, or intra-familial conflict or inconsistency.
Certain mental illnesses have a genetic component e.g. manic-depressive psychosis, and so are more likely to present in an individual (with or without mental retardation) where there is a positive family history.

- Social:

Behavioural problems may be the understandable reaction to life events, persisting communication difficulties with associated frustration, social deprivation, abuse or neglect, institutionalisation or infantilisation (being treated unnecessarily childishly).

- Emotional:

Children with mental retardation are at risk of abnormal emotional development, failing to form secure attachments and developing deficient personality structures. Such children are prone to react in stressful situations with symptoms of psychopathology including anxiety and depressive disorders.

- Educational:

Educational programmes pitched at either too high or too low a level may contribute to mental and behavioural disturbance because of either boredom or frustration and upset. The educational placement itself may also contribute. Learning with a disabled peer group may expose a child with mental retardation to modelling of inappropriate and maladaptive behaviours. Conversely learning with a more able group of classmates may highlight just how disabled children are, leaving them open to teasing, bullying, social isolation and the development of poor self-esteem.

- Maladaptive Learning:

All the above can interact with the child's propensity to learn inappropriate and maladaptive responses to situations where there is a problem in gaining attention, avoiding social interaction or difficult tasks, or in getting one's own way.

Which psychiatric diagnoses can be found in children with mental retardation?

All psychiatric diagnoses that are found in children without mental retardation can occur in those with mental retardation. Some psychiatric conditions such as hyperactivity, conduct disorders and adjustment disorders are, however, more frequent in children with mental retardation. Children with mental retardation are also more vulnerable to stressful events, loss and environmental changes.

What are the main treatment interventions for children with mental retardation and mental & behavioural problems?

Treatment interventions for problems encountered in children and young people with mental retardation should be multi-disciplinary and include:

- Medical:

Epilepsy can further aggravate mental retardation and can cause as well as exacerbate behavioural problems. Its presence in association with severe mental retardation is a potent vulnerability factor
predisposing towards psychological problems. Anticonvulsant medication should be combined with psychological approaches.

Physical disfigurement as part of a physical phenotype may cause profound distress in the child and family requiring long-term psychological support.

Psychiatric disorders warrant medical intervention such as the confirmed benefits of stimulant medication such as methylphenidate (Ritalin) for Hyperkinetic Disorder. Also other psychotropic medication such as antipsychotics and antidepressants may be useful.

- **Psychological:**

The impact on family functioning of the presence of a child with mental retardation can be profound. This in turn may aggravate the child’s problems. Thus family therapy may be indicated. More often behavioural approaches will be appropriate although other family members will need to be included to act as co-therapists. Behavioural approaches have limitations, which must be born in mind while devising and undertaking such interventions. Commonly experienced problems include:

- high response specificity to the environment in which the programme is undertaken i.e. the improvement may not generalise to different settings or different individuals
- a need for long-term intensive continuation of behavioural programmes to maintain benefits and prevent relapse.

- **Educational:**

Special education, whether in special school or with specialist input within a mainstream school, is of primary importance in addressing the needs of the child with mental retardation. Teaching programmes must be tailored to the child’s developmental level and be mindful of associated difficulties such as autism. The latter requires a particular emphasis on structured and predictable programmes with a focus on the multiple qualitative impairment in social functioning, language, and ritualistic tendencies, which are the hallmarks of the condition. Certain causes of mental retardation may require specific requirements for classroom adaptations, for example the gaze aversion, sequential information processing difficulties and numeracy problems often witnessed in Fragile X syndrome.

**What are Attention Deficits?**

Attention deficits and overactivity are common in children with mental retardation and are often consistent with the individual’s developmental level. Sometimes they may be particularly marked. There is evidence that certain genetic causes of mental retardation are more likely to lead to these difficulties, for example Fragile-X syndrome, Smith-Magenis syndrome and Sanfillipo syndrome. The following features require careful consideration in diagnosis:

- Inattentiveness - the child unable to concentrate for any length of time, even on enjoyed activities?
- Restlessness - the child unable to stay seated for any length of time? Is he always up-and-down from his seat even during mealtimes and other enjoyed activities?
- Fidgetiness - the child constantly twiddling his fingers and toes and shuffling around on his bottom when seated?
- Overactivity - he always on the go?
- Impulsiveness Is he the sort of child who always acts first and thinks later - if at all? Is he unable to wait before doing something?
- Distractibility Even when he does concentrate, is this extremely fragile so that even the slightest distraction breaks his concentration?

If all these features are present in a wide range of settings, irrespective of whom the child is with and what time it is (all-pervasiveness) then the child may have Hyperkinetic Disorder (or Attention Deficit Hyperactivity Disorder). This condition is known to have a biological basis to do with delays in maturation of certain parts of the brain. As well as requiring specialist educational and psychological input these children often benefit from judicious use of stimulant medications such as methylphenidate (Ritalin). These must always be prescribed and monitored by a professional experienced in this highly specialised field and only after a thorough and appropriate evaluation. Contrary to earlier beliefs, there is now evidence that some children with even severe mental retardation can respond beneficially to concentration enhancing approaches including stimulant medication.

**What are the main issues for adolescents with mental retardation?**

Separation and individuation issues are particularly complex for adolescents with mental retardation. The ongoing struggle between autonomy and dependency coexists with practical issues such as the development of sexual awareness and drives and the need to ensure individuals are protected from abuse and exploitation. Inability to achieve true independence from the family may cause depression and anger and other psychological disturbance including delinquency.
PERVARSIVE DEVELOPMENTAL DISORDER (PDD)

What is Pervasive Developmental Disorder?

PDD is seen as a continuum or spectrum of disorders. People with PDD fall along a continuum of diverse characteristics, all resulting from the underlying triad of impairments.

- impairment in verbal and non-verbal communication
- impairment in two-way social interaction (relationships)
- impairment of imaginative skills and limited interests

The diagnosis of PDD is made through recognising patterns of behaviour from early life.

How can you detect Pervasive Developmental Disorder?

The signs of PDD are difficult to detect in infancy and may go unnoticed by parents, though they often report that looking back, they knew something was wrong. As the child gets older, the developmental milestones may be late or in some cases, absent (i.e. no speech is developed) and often then parents begin to question the child's catalogue of odd behaviours and strange lack of interest in others.

What is Autism?

Autism is the most severe form of PDD, beginning usually in the first year of life.

What is Aspergers Syndrome?

Aspergers syndrome refers to those individuals with PDD who have normal or above normal intelligence level.

People with Aspergers syndrome have impairments in reciprocal social interactions resulting in a solitary lifestyle, language problems and difficulties with non-verbal communication.

Their all absorbing narrow interests make them stand out. Their lack of sensitivity for others capacity for discussing these favourite subjects makes most encounters one-sided and tedious.

Their difficulty in understanding that others have different thoughts and feelings from their own, makes the imposition of their routines and interests on others automatic. They also tend to be clumsy.

What is the prevalence of PDD?

PDD affects approximately three times more boys than girls and occurs across all cultures and all social classes.

Some studies, using a wide definition of the PDD spectrum found the prevalence of the triad of impairments to be 15 - 22 in every 10,000 children.

The prevalence of autism is 2-4 children in every 10,000.

What is the relationship between PDD and mental retardation?
Approximately one third of people with PDD have moderate to severe mental retardation. A further third have mild mental retardation, and the remainder have normal or above intelligence (Aspergers syndrome).

Autism is increasingly likely to occur in those who have severe mental retardation, though the reason for this association is not known.

**What are the causes of PDD?**

The exact causes of PDD are not clear, though biological and genetic research into autism is providing more clues as to its origin.

No one medical condition can be seen to be the cause of PDD, though a number of links have been made with the following conditions:

- Fragile X syndrome
- Rett's syndrome
- Phenylketonuria
- Tuberous Sclerosis
- Viral infections such as congenital rubella (measles)
- Difficulties experienced during the pregnancy, such as, late bleeding in the 4th-8th month
- Mothers over 35 years of age
- Complications at birth

These prenatal and postnatal conditions are only evident in a minority of children with PDD.

**What are the secondary psychiatric problems among individuals with PDD and mental retardation?**

Individuals with PDD come frequently into contact with psychiatric services because of their secondary psychiatric disorders. These include atypical psychotic states, manic-depressive disorder, impulse control disorder and different behavioural problems.

**Is there a treatment for autism?**

There is no cure for PDD.

Communication is a key factor in people's daily lives. It is vital to recognise an individual's communication strengths and needs, the need for predictability and structure and the difficulties with social interactions. Support should be provided on an individual basis and environments tailored to meet each individual's needs. This is necessary to enable individuals to learn and use skills and participate in daily living.
What is the prevalence of mental disorders in adults with mental retardation?

Adults with mental retardation are at increased risk of developing mental disorders due to the complex interaction of biological, psychological, social and family factors. Prevalence studies have consistently shown that 20-40% of people with mental retardation also have some form of mental disorder.

Professionals and staff unaccustomed to working with adults with mental retardation may inappropriately attribute signs of a mental disorder to a person's mental retardation per se - a phenomenon known as 'diagnostic overshadowing'.

What factors influence the presentations of mental disorders in people with mental retardation?

The presentation of a mental disorder in an individual with mental retardation will depend on his or her usual levels of cognitive, communicative, physical and social functioning, and usual behavioural repertoire, together with past and present inter-personal, cultural and environmental influences.

Generally, the signs and symptoms of mental disorders presented by adults with mild mental retardation and reasonable verbal communication skills are similar but less complex than those presented by adults with normal intellect. However, due to their less well-developed cognitive and communication skills, as well as increased risks of physical impairments, adults with moderate and severe mental retardation are more likely to exhibit disturbed and regressed behaviours, physical signs, and complaints as presentations of mental disorders. The possibility of underlying mental illness in people presenting with newly arisen behaviour disturbance must be considered.

An individual may present with overlapping signs and symptoms of two or more related mental disorders at a given time, as the clinical examples below illustrate:

- **Example A:**
  A man with mild mental retardation and epilepsy presented with long-standing excessive attention to his personal hygiene due to an obsessional personality disorder, together with recent panic attacks and hyperventilation due to an anxiety disorder.

- **Example B:**
  A middle-aged woman with Down syndrome and moderate learning disabilities presented with a recent onset of low mood, disturbed sleep and appetite due to a depressive disorder, set against a background of gradually declining social and self-care skills due to Alzheimer dementia.

- **Example C:**
  A teenager with severe mental retardation, no speech, social indifference, fear of water and finger flicking since childhood due to autism, presented with self-injurious and sexually inappropriate challenging behaviours following changes in his daytime activity programme.

What types of mental disorders may exist in adults with mental retardation?
Adults with mental retardation suffer from the same types of mental disorder as people with normal intellectual functioning. In adults with severe mental retardation, autism and behavioural disorders are common, but psychoses are often difficult to diagnose when individuals are unable to verbalise complex experiences such as odd ideas and hearing voices. The diagnosis of organic psychoses and personality disorders is difficult in most adults with mental retardation, as it is hard to obtain an accurate base line and long-term account of functioning, behaviours and symptoms.

The main types of mental disorders in adults with mental retardation are:

- **Psychoses**

These disorders may be misdiagnosed in adults with mental retardation exhibiting stress-related confusion, odd behaviour, muddled speech and suspiciousness. Classic symptoms are usually present but may be difficult to identify and be masked/overshadowed by atypical features, which can lead to diagnostic problems in schizophrenia and paranoid psychosis. Hysterical symptoms, pseudo-seizures, and visual hallucinations are common.

Affective (manic-depressive) psychoses often run in families and can present as cyclical manic, depressive or mixed disorders. Disturbed activity levels, biological and social functioning often accompany irritability in mania, and bodily complaints in depression. Regression, confusion, vomiting, self-injurious and aggressive behaviours may represent "depressive equivalents". Rapid cycles of bipolar disorder are particularly associated with mental retardation.

- **Neuroses**

These disorders are generally under-diagnosed, especially in adults with moderate or severe mental retardation.

Reactive depression commonly follows a life event such as the loss of a significant carer, friend or pet, or placement changes, but is often not recognised.

Anxiety states may develop in response to stress and environmental changes including resettlement. Anxiety may present with panic attacks, agitation, low mood, pseudo-seizures, and hypochondriacal, self-injurious and acting-out behaviours.

Phobias tend to be over-diagnosed - a refusal to try something new may represent more general avoidance of possible failure. However, specific phobias of dogs, scissors, dirt, water or heights, for example, do occur, particularly in people with autism. The repetitive thoughts and ritualistic behaviours that are resisted and cause anxiety to those with obsessive-compulsive disorder may be misdiagnosed as autistic features.

- **Personality Disorders**

Adults with mental retardation exhibit the full range of personality assets, difficulties and disorders. There is no universal agreement among specialists as to the existence of personality disorders in adults with mental retardation because of their different developmental process of personality due to their impaired intellectual and social functioning. However chronic maladaptive patterns of behaviour which are not adequately explained by other developmental or mental disorders, may be best explained as due to a personality disorder. Whilst personality disorders are more easily
diagnosed in adults with mild and moderate mental retardation, similar presentations in adults with severe mental retardation are more likely to be seen as challenging behaviours.

- **Organic Disorders**

Delirium is probably under-diagnosed. Acute confusion caused by constipation, medication, infections, or epilepsy may not be noticed. It usually resolves with treatment of the underlying causes.

Dementia is increasingly diagnosed as more adults with mental retardation survive into old age. Roughly 8% of adults with Down syndrome aged 35-50 years and 65% of those aged over 60 years will develop Alzheimer's dementia. Dementia may present with loss of skills, social withdrawal, behaviour problems, epilepsy, depression or incontinence. The inevitable functional and physical decline may be rapid. Reduced functioning in ageing adults with Down syndrome may also be due to their increased risk of developing a hearing loss, cataracts, depression and thyroid underactivity.

**What is involved in the assessment of mental disorders in adults with mental retardation?**

Multidisciplinary assessment is always indicated in mental retardation. Specialist psychiatric assessment is necessary, given the complex combination of mental health, physical health and social care needs presented by people with mental retardation and mental disorders.

Psychiatric assessment focuses on whether or not the adult with mental retardation has a mental disorder; i.e. should the individual be considered as having ‘dual diagnosis’ i.e. mental retardation and mental illness or disorder? Ideally, the multidisciplinary approach is adopted involving the client, carers and other agencies to maximise the gathering of developmental, background, functional, behavioural and observational data. Assessment should cover the client’s usual and recent communication skills, functioning, personality, relationships, environments, service inputs, behaviours, medication and physical health (for example: epilepsy) to determine any changes.

Verbal communication, hearing and co-operation skills determine whether mental state assessment can include behavioural observations at interview of speech, mood, thoughts, perceptions, orientation, memory and insight about their condition and needs. Presenting needs, past and present physical, mental and social functioning are then formulated to try to make a specific diagnosis (if possible) and agree a needs-orientated clinical intervention plan with the client, carers and other agencies.

Further professional and carer reports, behavioural observations, physical and psychometric investigations, reassessments in other environments, and trials of medication may be necessary as part of the ongoing clinical assessment and care plan.

Several assessment instruments are currently in use including the PIMRA (Psychopathology Instrument for Mentally Retarded Adults), the Reiss-Screen for Adults and Children, and the PAS-ADD (The Psychiatric Assessment Schedule for Adults with Developmental Disability) and the Developmental Behaviour Checklist for Children (DBC). Their usefulness in clinical practice still needs to be proven but they have been widely used in research.

**What treatment methods are available for people with mental retardation and mental disorders?**
Over the last 10 - 20 years there has been a large increase in the number of different treatments available for various types of mental disorder.

Just as psychological, physical and social factors working together contribute to the development of a mental disorder, a range of psychological, physical and social treatment strategies are available to treat a mental illness. Experience suggests the best results are obtained when the treatment package encompasses all three treatment modalities although often it is the case that, according to the clinical situation, one type of treatment e.g. the use of anti-depressant medication or a behavioural therapy intervention may predominate.

**What types of psychological treatments are mostly used?**

These include behavioural therapy, psychotherapy, and cognitive therapy.

- **Behavioural Therapy:**

In behaviour therapy, the clinician attempts to alter a prominent behaviour by replacing it with an incompatible behaviour. For instance the avoidance behaviour in phobic disorders is treated by encouraging the patient to enter situations he fears (this is called exposure therapy); or unwanted behaviours are ignored whilst more positive socially valued behaviours are rewarded. Behaviour therapy can be used in people who have limited or no verbal communication skills. Behavioural intervention will not work if the patient is intent on sabotaging the behavioural intervention plan.

Many behavioural interventions are available. The decision as to which one is chosen depends on a variety of factors, including the nature of the problem, the patient’s ability to co-operate, staff skills and the treatment setting.

The interventions should be socially acceptable and above criticism on moral and ethical grounds. Practitioners who are going to implement it should participate in its design. This will allow them to state whether they will be able to carry out the plan and facilitate "ownership". Behavioural interventions must be designed and supervised by a clinical psychologist, implemented by trained staff and properly monitored.

The effectiveness of the intervention should be reliably monitored: for example, by recording the frequency of the behaviour. This enables an objective assessment of whether or not the plan is successful.

Interventions should not be perceived as being able to be applied in the same way to each individual. Each intervention should be adapted to meet the needs of a given situation.

Using a behavioural intervention does not necessarily discount the use of other therapeutic approaches. Other types of therapy, such as counselling and medication, can be used instead of or in tandem with behavioural interventions as long as those implementing the plan are sufficiently qualified in the given area.

Some examples of behaviour therapy currently used for people with mental retardation are:
- Positive Programming

Positive programming strategies are usually defined as "a gradual educational process" for behaviour change; a process that is based on a functional analysis of the presenting problems and which involves systematic instruction in more effective ways of behaving.

For example: one man would always start screaming if he was asked to work for a given length of time. He would walk away and then return to the task.

A functional analysis indicated that he was using screaming to indicate that he wanted a break and that he wanted to choose his tasks, like hoovering, for the day. The alternative strategies that he was taught to use were:

- he planned his day each morning
- he was given a card that he handed to staff to indicate that he wanted a break
- positive reinforcement of desirable behaviour

The reinforcer should have positive value for the individual and be one that is age-appropriate and socially acceptable. For example, it is of little use to teach someone to stop hitting people by giving him or her a Mars Bar every time he/she does not. Such a scenario may well lead to an obese individual who expects to eat Mars Bars all the time.

- Stimulus Overcorrection / Saturation

Overcorrection is a procedure whereby the individual is encouraged to continue the negative behaviour again and again with the expectation that such repetition will lead to the cessation of the behaviour. It is an aversive procedure and should only be used as a last resort when all other possibilities have been exhausted.

Stimulus saturation, however, is not an aversive procedure. It enables the individual to have access to the reinforcer that is maintaining the desired behaviour.

For example: one man was always searching for a cup of coffee to drink in the factory where he worked. Flasks of coffee were placed at strategic points. This enabled him to realise that he could have coffee as and when he wanted and there was a subsequent decrease in the amount of coffee that he wanted.

- Psychotherapy:

In the field of mental retardation there has been an ongoing debate as to whether individuals who are cognitively impaired can benefit from psychotherapy. Some very intelligent people are unable to see or understand their problems in mental terms i.e. they find it difficult or impossible to "get in touch with their emotions". Conversely an individual who is less intellectually gifted may have a rich mental life with which he is fully in touch. Mild to moderate mental retardation in itself is not a contra-indication to counselling or even psychoanalysis as long as the person understands the purpose of the treatment and is motivated. Unfortunately some individuals with mental retardation tend to have "concrete thinking" (as do some people in the general population) i.e. they cannot link their thoughts and behaviour to their emotions, and these individuals are not good candidates for psychotherapy.
People with severe/profound mental retardation are not suitable for psychotherapy - they may or may not have a rich "mental intelligence" but their extremely limited intellectual abilities (often coupled with limited or non-existent verbal skills) means that a psychotherapeutic approach is not practical. There are non-verbal forms of therapy to address the emotional needs of these individuals such as art therapy, drama therapy, music therapy etc. They make use of some of the principles mentioned above such as trust, ventilation of feelings, restoration of morale etc., using different media.

Patients who are severely depressed or anxious are unlikely to benefit from psychological treatments in general. This is because their concentration and memory may be poor or they are so preoccupied by morbid thoughts that they cannot make use of the therapist. In these situations psychotropic medication is generally the first treatment line.

Both individual and short psychotherapy are suitable techniques. Psycho-therapy must only be undertaken by appropriately trained professionals.

- Cognitive Therapy:

Cognitive therapy can be useful in patients with mental retardation suffering from mild to moderate depression, anxiety disorders, panic disorder and obsessional compulsive disorder. It is clear that as well as being motivated the patient must be able to communicate the content of their thoughts to a therapist and have a clear understanding of the treatment process and its aims.

Cognitive therapy is also used for people with mental retardation who have problems with anger control. These techniques include the client learning to analyse the environmental stimuli that act as triggers for them and to learn self control techniques that enable them to develop alternative behaviours to each stimulus.

**What types of physical treatments are available?**

These mainly include psychotropic medications and very rarely ECT.

**What are the indications for prescribing psychotropic medication in mental retardation?**

The indications for the use of psychotropic medication in mental illness in people with mental retardation are exactly the same as their use in the general population.

Choice of drug and route of administration depends upon the diagnosis, severity of illness and the physicians' knowledge and experience of the range of drugs available.

When prescribing psychotropic medication the golden rule is that the benefit should outweigh the side effects. Of course, this applies to all forms of therapeutic intervention, including psychological and social treatments. If we take depression as our starting point, anti-depressants would be considered if the intensity of the depressive episode was moderate to severe. General indications include the presence of "biological symptoms" (loss of appetite with weight loss, insomnia, psychomotor retardation, loss of libido, diurnal variation of mood, and, among women, amenorrhea) - they are less usual in mild depressive disorders but particularly common in the severe forms. Other indications would include the presence of suicidal ideation and any psychotic features (although in these cases ECT and the possibility of admission to a psychiatric unit would also be considered).
Finally the presence of a strong genetic element, which would imply a more biologically based aetiology to the depressive disorder, a history of previous beneficial outcomes with anti-depressant treatment and the failure of psycho-social interventions in alleviating the depressive disorder would also influence the clinician.

Antipsychotics (also known as neuroleptics or major tranquillisers) are indicated in all psychotic disorders regardless of their aetiology. They eliminate or reduce psychotic phenomena in up to 70% of patients suffering from a psychotic illness. They are also used in mania and in challenging behaviour, particularly where a client is over aroused or the behaviour presents a danger to themselves or others. In this case the treatment often creates a window of opportunity for new, safer behaviours to be learned. They may be used as adjunctive therapy for some severe anxiety disorders. There are other indications for these medicines but these are the most common uses. In recent years newer antipsychotics have come on the market such as sulpiride, clozapine, risperidone, olanzapine, seroquel (quetiapine fumarate). The advantages that these drugs possess over the older neuroleptics such as chlorpromazine and trifluoperazine are that they tend to have better side effect profiles especially for long term use. This is particularly true for extra pyramidal side effects such as parkinsonism and tardive dyskinesia. In general these newer drugs are to be preferred unless there is a specific contraindication.

In some cases, it is preferable to administer an antipsychotic in the form of a depot preparation that is given intra muscularly once every few weeks. Depot medication, like all other types of medication, can only be given with the patient’s consent or if they are unable to give their informed consent, with the proxy consent allowed under local laws. Indications for using depot formulations instead of oral medication include poor patient compliance or when there is concern regarding the absorption or metabolism of oral drugs. The major disadvantage of depot injections is that if the patient suffers a concurrent physical illness or serious side effects from the medication, the drug will stay in the body for several weeks.

Are there differences in doses and side effects of psychotropic medication used for people with mental retardation than those without?

People with mental retardation, particularly those with more severe disabilities, can be sensitive to medication. Psychotropic medication should therefore be prescribed cautiously, starting from low doses and gradually increasing as necessary. Careful monitoring is necessary as some people with mental retardation, particularly those with more severe mental retardation, often do not recognise or report side effects.

What are the most commonly used medications for people with mental retardation and psychiatric disorders?

The medications most commonly prescribed for persons with mental retardation and mental illness fall into the following classes:

- Antipsychotics (neuroleptics, major tranquillisers)
- Anti-depressants
- Mood-stabilising agents
- Sedatives (hypnotics)
• Anxiolytics

Antipsychotics

Antipsychotics are used for the treatment of psychotic illnesses and other disorders such as Tourette’s syndrome and to suppress aggressive behaviour, control self-injurious behaviour, or treat other severe behaviours that are resistant to more specific treatments. Their use for the control of behavioural problems remains controversial.

- Examples:

The availability, usage, and indications for all medications vary nation by nation. Indeed, prescribing practices can vary greatly even within a given country. Examples of traditional or typical antipsychotics include thioridazine, haloperidol, chlorpromazine, trifluoperazine and many others. They provide psychotic relief through a non-specific mechanism of dopamine blockade.

Atypical or novel anti-psychotics include (at the time of writing) clozapine, risperidone and olanzapine. They are atypical primarily due to their far greater affinity to block serotonin receptors and to a lesser extent dopamine receptors. Experience with these agents in this population is greatest with risperidone. Clozapine is useful in treatment-resistant schizophrenia but may cause neutropenia. Several more atypical agents will soon be available.

Anti-depressants

Antidepressants are used primarily for the treatment of depressive mood disorders. The newer antidepressants, often referred to as Serotonin Selective Reuptake Inhibitors (SSRIs), have become the agents of first choice in most cases. They have also been used in the treatment of self-injurious behaviour, obsessive-compulsive disorder, panic disorder, and Tourette’s syndrome. Older agents still have a role but are more likely to cause unpleasant and problematic side effects and are less safe in overdose.

- Examples:

• Older tricyclic anti-depressants: amitriptyline, dothiepin, nortriptyline, and imipramine
• Newer anti-depressants: sertraline, fluoxetine, fluvoxamine, nefazodone, and clomipramine (clomipramine is a tricyclic which differs from the others in this group)
• Monoamine oxidase inhibitors (MAOIs): phenelzine, are rarely used in mental retardation due to side effects

Mood-Stabilising Agents

The so-called mood stabilising agents are used for people suffering from "mood swings", commonly referred to as bi-polar affective disorders or manic-depressive disorders. The medications prescribed are diverse but have in common a propensity to stabilise central neuronal activity. These same medications are also used to treat non-specific aggression and over-aroused behaviour of people with mental retardation and as adjunctive therapy for unipolar depressive disorders and psychotic disorders.
Lithium has a narrow therapeutic range and can cause some serious but manageable side effects. Despite this, it has proved to be a mainstay in the treatment of these disorders. Carbamazepine and valproate are anti-convulsants that are widely used but may cause elevated liver enzymes and blood dyscrasias. All three require monitoring of serum concentrations. Lithium is cleared by renal excretion and requires kidney function monitoring. It can also be thyrotoxic and therefore thyroid functioning should be regularly monitored.

Clonazepam is a benzodiazepine. It allows for very flexible dosing patterns and does not require blood draws. However, as a benzodiazepine it should be approached cautiously. It is also very effective in treating panic disorders and to a lesser degree other anxiety disorders.

- Examples:
  - Lithium, carbamazepine, valproic acid derivatives, and clonazepam

Sedatives (Hypnotics)

People with central nervous system injury often present with disturbed sleep patterns. All aspects of sleep architecture may be involved. Foreshortened sleep poses considerable problems to caregivers. Chronic sleep deprivation, including that caused by sleep apnoea syndromes, can create new or exacerbate existing mental health problems. Traditionally, the most commonly used sedative agents are the benzodiazepines. Benzodiazepines can cause problems particularly tolerance and addiction if used incorrectly. Some members are better at relieving anxiety than promoting sleep.

Some non-benzodiazepine medications are useful in sleep and may be safer and easier to use.

- Examples:
  - Benzodiazepines: diazepam, nitrazepam, lorazepam, alprazolam, clonazepam, and flurazepam
  - Non-Benzodiazepines: diphenhydramine, and zolpidem

Which are the most commonly used drugs for anxiety?

Anxiety disorders constitute a very diverse group. Generalised anxiety is often first treated with medications such as hydroxyzine and buspirone. If these are unsuccessful, benzodiazepines are often used such as; diazepam, lorazepam, or alprazolam. Panic disorder may be treated using Serotonin Selective Reuptake Inhibitors (SSRIs) or clonazepam. Obsessive Compulsive Disorder is usually treated with SSRIs as the first line treatment. Post-Traumatic Stress Disorder (PTSD) is treated using various agents including some for the symptomatic relief of nightmares by suppressing REM sleep.
CHALLENGING BEHAVIOURS (BEHAVIOUR DISORDERS)

What does the term challenging behaviour mean?

This term refers to severe and usually chronic combinations of aggressive, destructive, attention seeking, sexually inappropriate, self-injurious, noisy, hyperactive, and socially inappropriate (for example: pica, faecal smearing or running away) behavioural disorders. Such behaviours present challenges for service providers as they threaten the physical safety of the client and others and the client risks exclusion from mainstream services. The term "challenging behaviour" was coined so that rather than the problem being viewed as residing in the person, it was instead seen as a challenge for services to overcome.

The term challenging is also increasingly being applied to people with and without mental retardation who exhibit dangerous behaviours including fire-setting, assault, sexual offending, stealing etc.

Aggressive and destructive challenging behaviours are usually chronic and often have some communicative function. They may represent attempts to protest, attract attention, express anger, sadness, fear or confusion and even to indicate feeling physically unwell. They are more likely when clients have low frustration tolerance, communication impairments, poor social skills and variable supports. Attention-seeking behaviours may include persistent complaining, crying, bodily concerns and dramatic acts. Sexually inappropriate behaviours include touching and grabbing, stripping, self-exposure and public masturbation. Such behaviours are usually the consequences of general social disinhibition rather than previous abuse.

Challenging behaviours may be associated with pica, stereotypes and hyperactivity. Pica is the persistent eating of non-nutritional substances including paper, dirt, hair, paint and cigarette stubs. Stereotypes are repetitive primitive and self-stimulatory movements such as body rocking and head-shaking. Stereotypes and pica tend to occur in people with severe mental retardation, limited mobility, communication and social skills, who are living in impoverished environments. Some children, especially those with severe mental retardation and language disorders, are hyperactive. They are overactive, impulsive and destructive with a short attention span, but after adolescence most become apathetic and socially withdrawn.

What about self-injurious behaviour (SIB)?

Self-injurious behaviour occurs in 2-13% of people with mental retardation and is commoner in males, people with severe mental retardation and people with autism. It includes skin picking, biting, scratching, head banging, face-slapping, hair-pulling, eye poking and anal-poking. It can cause brain and tissue damages and may become life threatening. Complex overlapping attention seeking, task-avoidance, and socially aversive and self-stimulatory functions may maintain these behaviours. Physical, mental and environmental factors can also contribute to the development and maintenance of self-injurious behaviours; for example: earache, constipation, anger, anxiety, depression, under-stimulation, environmental and staff changes.

What are the causes of challenging behaviours?

The cause of challenging behaviours is usually multifactorial and include:
- **Biological causes**

There are some syndromes, which clearly have behavioural manifestations e.g. Lesch-Nyhan and self-injury, and Prader-Willi and overeating.

There is also considered to be a link between epilepsy, organic brain damage and challenging behaviour (although clearly not in all cases) and also autism and challenging behaviour.

Challenging behaviour can, however, have a physical cause. It can be caused by pain or following illness. For example, persistent pain could lead to self-injury, making noise, aggression; while the consequence of illness could be refusal to participate in activities, withdrawal etc. This could occur due to fatigue as much as any other causes.

- **Challenging behaviour as a response to a poor environment**

People with challenging behaviour are most at risk of ending up in the poorest quality environments. They are known to be the most likely to be admitted and re-admitted to hospital, and the opportunities for participating in a range of activities are usually restricted for them. Their history, therefore, and (in some cases) present treatment can be characterised by a barren environment with few materials and activities, low levels of social interaction and those interactions being negative and demanding rather than positive and supportive.

- **Challenging behaviour as learnt behaviour**

Challenging behaviour can be learnt in the same way as any other behaviour can be learnt: by the presentation of rewards following the behaviour. The behaviour may not, initially, occur with the intention of gaining a reward, but if an individual engages in a behaviour and there is a consequence which they find pleasant, then they will eventually learn to pair a behaviour with a consequence. (Similarly, if the consequence is punishing, then the assumption is that eventually the behaviour will disappear.)

There are two ways in which behaviour can be rewarded. The first is by positive reinforcement: i.e. something good/rewarding is given; and the second is by negative reinforcement: i.e. something unpleasant is taken away.

- **Challenging behaviour as a communicative act**

This understanding that there are different types of reward associated with challenging behaviour has led to an acceptance of the hypothesis that such behaviours might have a communicative function. This is especially true in the situation where the individual finds usual methods of communication difficult - if not impossible.

- **Challenging behaviour as a response to mental trauma**

People with mental retardation are subject to a range of responses from those around them, some of which may be supportive and some of which may be abusive. The abuse can be physical, sexual or mental, and all of these will have an effect on the individual. Challenging behaviour can also be an
expression of anger or misery or pain at the fact of being disabled and the life experiences to which it has led.

- **Challenging behaviour in relation to a mental illness**

People with mental retardation can also suffer from a mental illness that can effect their behaviour. It is important to exclude diagnosable mental illness as a cause of challenging behaviour.

**Which are the current ways of responding to challenging behaviours?**

A full mental state and physical assessment is essential to exclude biological causes. Investigations should include an EEG if occurrence of brain damage is suspected.

A full functional analysis of the behaviour repertoire should be carried out. Functional analysis provides a comprehensive assessment of people with mental retardation and challenging behaviour. For example if a person has been reported to be hitting their head against objects, then the first action that should be taken is a functional analysis of the problem. Functional analysis does not focus solely on the problem behaviour. It attempts to analyse the function of the behaviour by a thorough investigation of the context in which the behaviour occurs.

There are three main areas to be considered:

- the person who is referred
- the persons situation or environment
- the significant people in the persons life

Using a variety of techniques, such as questionnaires, interviews and observation, information is gathered. Base-line data on various aspects of the person’s life are collected. Carers and/or the person are asked to record the frequency of the behaviour and possible reinforcers. Staff may be asked to use ABC (Antecedent, Behaviour and Consequence) charts to try to investigate the behaviour further. With these charts, staff record events just before (antecedent) and just after (consequence) the target behaviour. In addition, a diary of daily activities and information on the person’s life history may help in the understanding of the behaviour.

Once the information has been collated and summarised, it should become possible to formulate hypotheses as to the origin and critical function of the behaviour and hence design a suitable intervention. It is important to remember that rarely does a behaviour have a simple function. More often, a behaviour has a number of functions, and a function may not be related either to the antecedent or to the consequence.

As well as providing a helpful environment, teaching new skills and structuring reinforcement to help replace behaviours, staff also need to know how to respond when the behaviour does occur. Challenging behaviour does not disappear overnight and, in many cases, does not disappear completely at all. These may include a range of interruption strategies such as redirection, instructional control, assisting the person to relax etc. Giving as required medication may also be part of a reactive strategy and (hopefully not frequently) breakaway and/or control and restraint procedures. If restraint procedures are to be used, then all staff need to be trained in them by an instructor qualified to do so. Guidelines must be regularly reviewed and monitored.
It needs to be clearly understood that these are not treatment strategies, they are instead a way of coping with the situation through a series of stages.

It should be pointed out that behavioural analysis and design or interventions should only be carried out by a clinical psychologist or a trained behaviour therapist and must be properly supervised.

**Supporting staff working with people with challenging behaviours**

There is increasing recognition of the stress of supporting people with challenging behaviour, especially in the long term. It is clear that any approach to working with challenging behaviour must include not only staff training, but also formally organised staff support. Good management and staff support is crucial if staff are to be enabled to work effectively with clients with challenging behaviour.
EPILEPSY

How common is epilepsy in mental retardation?

There is a strong relationship between severe brain damage, severe mental retardation and epilepsy. The prevalence of epilepsy in people with severe mental retardation is 30%, and in people with profound mental retardation, 50%. In contrast, the prevalence for people with mild mental retardation is 6%. There is also a strong positive association between mental disorders and epilepsy.

People with Down syndrome now have an increased life span and epilepsy is being diagnosed more frequently. Recent studies have shown that the incidence of epilepsy increases with age. It seems likely that this may be linked to the Alzheimer-like changes seen in such individuals.

The diagnosis of epilepsy in people with mental retardation can be difficult as the person may be unable to give a clear account of their symptoms.

It can be difficult to differentiate epilepsy from non-epileptic behaviour. Aggression, bizarre behaviour, abnormal motor activity, neurological deficits, the side-effects of drugs, self-injurious behaviour and generalised poor response to the environment may all be part of the repertoire of a person with mental retardation without the presence of epilepsy. However, such features may be present alongside epilepsy. A detailed account by an observer of the suspect behaviour is invaluable in making a diagnosis.

What are the main forms of epilepsy?

There are two groups of seizures, partial and generalised. The abnormal brain activity that causes simple partial seizures arises in a localised or focal area of the brain. The patient may complain of butterflies in their stomach, a tingling sensation, etc. These are auras. There is no impairment of consciousness and the client is able to answer questions during them.

In complex partial seizures, there is some impairment of consciousness. There may be abnormal behaviours e.g. lip smacking, chewing, fiddling with clothes and the client seems to be in a trance. This abnormal brain activity may spread to other areas of the brain resulting in a secondary generalised seizure.

In primary generalised seizures, there is no focal onset. Generalised seizures involve both sides of the body at the same time e.g. tonic-clonic (old term: grand mal), myoclonic, atonic, absence (old term: petit mal)

The doctor will seldom have the opportunity to witness an epileptic seizure and will have to rely on descriptions given by carers. Accurate information on the frequency, nature and timing of seizures will help to diagnose what sort of seizure is occurring, what medication to give, as well as when to give it. Therefore, it is important that carers keep a record of seizures and this is brought to clinic. It may be that seizures tend to occur at a particular time. Medication can be altered to overcome this. Some women experience increased seizures around menstruation and may need extra medication at that time.

At first presentation epileptic fits should be thoroughly investigated including EEG studies.
What are the principles of anti-epileptic treatment?

Different anti-epileptic drugs treat different types of epilepsy. Thus, it is important to know which types of epilepsy the client suffers.

The aim of therapy is to prevent seizures with as little medication as possible. Medication is generally started at a low dose and slowly increased to a dose that controls the epilepsy. However, many clients have severe epilepsy and require more than one drug to achieve satisfactory control. If more than one drug is used, note that nearly all anti-epileptic drugs interact with each other. For instance phenytoin is effective only when the blood level is within a certain range, another drug may alter its blood level so that it is no longer within the therapeutic range. Withdrawal of medication should be done gradually for fear of a rebound increase in seizures.

Many anti-epileptic medications are sedative which can lead to drowsiness and poor concentration. In people with mental retardation, these medications can further impair their ability to learn. Phenobarbitone is the worst culprit and most people have now been weaned off phenobarbitone and put on newer drugs. In the past few years, a number of new drugs; lamotrigine, vigabatrin, gabapentin and topiramate, have come on the market.

Anti-epileptic drugs need to be taken over a long period of time and require careful monitoring and regular blood level checks.

Which are the most commonly used anti-epileptic drugs?

The more commonly used anti-epileptic drugs and their more common side-effects are described in alphabetical order.

- **Carbamazepine**

  Carbamazepine (Tegretol) is used to treat all forms of epilepsy except absence seizures. As people with mental retardation often have more than one sort of epilepsy, carbamazepine is frequently the medicine of choice.

  - **Side-effects**

    A common side-effect is a generalised rash which goes away when the medicine is stopped. Nausea and vomiting may occur. Toxicity presents as dizziness, drowsiness and visual disturbances. Blood dyscrasias are a potentially fatal rare side effects. These should be suspected if the client develops a persistent fever, sore throat, rash, bruising or bleeding.

  - **Monitoring**

    The blood level should be taken if toxicity is suspected. As people with mental retardation may be unable to articulate toxic - side effects, regular monitoring of blood levels may be prudent.

- **Diazepam (Stesolid)**

  Stesolid is the name of the tubes of diazepam given by rectum in status epilepticus. Diazepam belongs to the group of drugs known as benzodiazepines which has been covered earlier under sedatives (Hypnotics).
- **Ethosuximide (Zarontin)**

  **Uses**

  Ethosuximide is the drug of choice in absence seizures.

  **Side-effects**

  It causes nausea and vomiting, and drowsiness, which can be reduced by slowly introducing the drug. It can also cause behavioural disturbances. Rarely, ethosuximide causes blood dyscrasias.

  **Monitoring**

  Drug levels should be checked. Blood tests can be done to exclude blood disorders.

- **Gabapentin (Neurontin)**

  **Uses**

  Gabapentin is added onto other anti-epileptic drugs to treat partial seizures.

  **Side-effects**

  Drowsiness, dizziness and unsteadiness are common. Headache, double vision, tremor, nausea and vomiting can also occur.

  **Monitoring**

  Unnecessary

- **Lamotrigine (Lamictal)**

  **Uses**

  Lamotrigine was introduced as add-on therapy but is now licensed to be used on its own for partial seizures and some sorts of generalised seizures.

  **Side-effects**

  Rash is a common side-effect; the likelihood of occurrence can be reduced with slow introduction of the drug. Headache, nausea and vomiting, double vision and unsteadiness can also occur. Rarely blood dyscrasias occur.

  **Monitoring**

  Routine checks of drug levels are unnecessary.

- **Phenobarbitone**

  **Uses**

  Phenobarbitone is used to treat all forms of epilepsy except absence seizures. Primidone (Mysoline) is converted to phenobarbitone and this is responsible for its anti-epileptic action.
- **Side-effects**

Phenobarbitone is highly sedative. It can cause confusion in the elderly. In children, it can cause paradoxical excitement and restlessness. Drug withdrawal should be undertaken slowly to avoid a rebound increase in seizures.

- **Monitoring**

Blood tests for the level of drug in the blood can help to indicate the dose a client should be taking.

  ➢ **Phenytoin (Epanutin)**

- **Uses**

Phenytoin is a very effective drug used to control tonic-clonic, simple and partial seizures.

- **Side-effects**

As with most anti-epileptic drugs, clients may feel sedated. It is important to watch out for toxic side-effects: the client may feel dizzy, have double vision, headaches or be ataxic, the frequency of seizures may dramatically increase. People who have been on phenytoin for many years may develop some coarsening of facial features, an acne-like rash and growth of the gums.

- **Monitoring**

To be effective, the level of drug in the blood must be maintained at a certain level.

  ➢ **Sodium Valproate (Epilim)**

- **Uses**

Sodium valproate is effective against all forms of epilepsy.

- **Side-effects**

It is generally well tolerated although sedation can occur. Some people suffer with gut symptoms i.e. nausea, vomiting, heartburn. Increased appetite and weight gain is a common problem. Rarely, hair loss occurs but this recovers when the drug is stopped. At high doses, tremor may occur. Very rarely, sodium valproate damages the liver. The client may feel unwell and be jaundiced; seizure control may be lost.

- **Monitoring**

Routine blood testing is unnecessary. However, blood levels are sometimes done to make sure that the drug is being taken.

  ➢ **Topiramate (Topamax)**

- **Uses**

This anti-epileptic drug is used as add-on therapy for partial seizures with or without generalised seizures.
- **Side-effects**

Sedation may occur.

- **Monitoring**

Blood level monitoring is not necessary

- **Vigabatrin (Sabril)**

- **Uses**

Vigabatrin is used in chronic epilepsy not satisfactorily controlled by other anti-epileptics. It is used to treat complex partial seizures and tonic clonic seizures.

- **Side-effects**

Sedation is common. Some people develop behavioural disturbances including irritability, nervousness, depression and aggression. Rarely, they may become psychotic. Therefore, it is prudent to avoid using this drug in those with a history of mental illness.

- **Monitoring**

Blood level monitoring is not necessary.
MENTAL HEALTH SERVICE

What type of Service is required?

People with mental retardation and mental health and behavioural problems require Specialised Psychiatric Services with appropriately trained and experienced doctors, psychologists, nurses and other staff.

Why are specialised services necessary?

Specialised Services are required because:

- the diagnosis of mental disorders in people with mental retardation poses special problems and requires special skills and expertise
- highly specialised assessment and treatment techniques are needed for the management of many problems
- therapeutic interventions often require modification to take account of intellectual and other limitations
- special regimes and careful monitoring of drug treatment is necessary because of the high frequency of side effects and unusual responses
- treatment, rehabilitation and aftercare must take account of any coexisting physical disabilities which frequently complicate mental retardation

Specialist services maximise staff skills and competencies, increasing the probability of effective and successful treatment and provide a base for teaching, training and research.

Why aren't mainstream mental health services suitable?

Attempts to provide mainstream psychiatric services for people with severe levels of mental retardation have generally proved less than successful because:

Staff do not have the necessary skills and resources to assess and manage the care in the community.

- If admission is needed patients with mental retardation may not mix well with other mentally disordered patients
- Patients with mental retardation are vulnerable and generally disadvantaged in such settings
- The pace of ward life is too fast for them
- it is difficult to gear therapeutic interventions to meet their special needs
- because of the small numbers involved it is impossible for staff to gain the necessary experience and expertise

There are often major difficulties in accessing generic services and territorial disputes can leave people with mental retardation stranded between mental retardation and mental health services without appropriate treatment.

If mainstream services are the only service available:

- key medical and nursing staff should receive appropriate specialist training
• guidelines on general approaches and management should be drawn up for all staff
• initiatives should begin to establish at the minimum a specialist community team and a
  specialist inpatient assessment and treatment facility

What are the main elements of a Specialist Mental Health Service for Mentally Retarded People?

A comprehensive service should provide:

• for all clinical and diagnostic groups including those with behavioural problem/challenging
  behaviour and offenders.
• for all age groups including children, adolescents and the elderly
• for all levels of mental retardation from borderline to severe/profound
• a range of services including community diagnostic and treatment services, inpatient
  facilities for acute treatment and continuing care, rehabilitation and aftercare
• a full range of treatment approaches including drug therapy, behaviour therapy, counselling
  and psychotherapy

What Inpatient facilities are required?

There should be a sufficient number of treatment settings to enable specialised treatment
programmes to be developed for each of the main clinical groups. The minimum requirement is
separate settings for the mentally ill, the behaviourally disturbed and offenders.

Mixing these groups in a single multipurpose unit makes it difficult to develop specific treatment
programmes.

Specialist services, including residential treatment units with appropriate levels of security, are
required for offenders with mental retardation.

What Community Facilities are required?

The complexity and chronicity of many psychiatric disorders suffered by people with mental
retardation often precludes their immediate return to ordinary community facilities. Such individuals
require specialised community settings with a structured environment and specially trained staff in
the short and sometimes in the longer term.

Specialised community services for rehabilitation and aftercare include:

• support personnel and specialist teams
• day treatment facilities
• training and recreational facilities
• residential provision - hostels, group homes

How should Specialist Psychiatric Services be organised?

It is very difficult to provide a fully comprehensive, therapeutically and financially viable service to a
small district/area because of the small numbers of individuals involved and the wide spectrum of
morbidity, age and disability levels. Whenever possible services should be developed on a multi-
district level.
FAMILIES AND CARERS

Why are families and carers important?

Family support and co-operation can be a critical factor in the success of treatment particularly in-patients living at home or returning home after a period of hospital treatment.

What do families and carers need to know?

Families and carers need help in understanding the nature of the disorder and its origins.

They should also be kept fully informed and be involved in discussions about the treatment/management programme, its aims and rationale.

What help and support do families and carers need?

Families and carers may require:

- opportunities to vent their anxieties and feelings
- help in accepting and adjusting to the situation
- advice and support on a number of practical issues

When is more intensive support/ intervention required?

More intensive support or interventions including individual counselling or in some cases family therapy may be indicated if:

- there are significant problems of adjustment to, for example, offending behaviour
- there are specific problems in the family psychodynamics, which have played a part in causing or perpetuating the disorder

A careful assessment of the benefits and the families/carers capacity to respond and co-operate is essential before embarking on an intensive programme of intervention.
OFFENDERS WITH MENTAL RETARDATION

What is the size of the problem?

The incidence of offending in people with mental retardation is much lower that in the general population.

Mental retardation in many goes undetected and they are imprisoned.

As a group they require special consideration because of their special treatment and management needs.

What types of offences do they commit and what are the causes?

Property and technical offences are the commonest offences committed by people with mental retardation. Sex offences and arson are over-represented. Violence is uncommon.

In general the bulk of offending in people with mental retardation is a consequence of under-socialisation, poor internal controls and faulty social learning compounded by educational underachievement, limited social and occupational skills and low self-image.

As in the general population an unstable upbringing and a range of adverse social factors are associated with delinquent behaviour.

Lack of normal sexual outlets compounded by sexual naivety, poor impulse control and poor interpersonal skills are the most common factors in sex offending.

Fire setting is usually the consequence of displaced aggression in rather passive individuals with poor verbalising skills.

What type of Treatment Programme is required?

Offenders with mental retardation require treatment and care not punishment.

The key components of a treatment programme are:

- general measures aimed at improving general skills and self worth including life skills training, education, counselling, socialisation programmes
- offence specific Interventions geared to the particular offence including behavioural management programmes, relaxation therapy, anger management, assertiveness training, drug therapy
- relapse Prevention including understanding the offence cycle, coping and escape strategies
- rehabilitation and Aftercare

What type of Service Provision is required?

Management of offenders with mental retardation requires close co-operation between the probation service, social service and psychiatric services.
A specialist forensic mental retardation psychiatric service is required. Because of the small numbers involved, a viable service is generally provided at a regional or sub-regional level.

The majority of offenders with mental retardation can be managed in the community with support from the various agencies.

Residential treatment/management is indicated:

- if the offence is serious
- if the client is considered to be a danger to himself or others
- if the client's needs for training, care and control cannot be met in a community setting

A comprehensive psychiatric service for offenders with mental retardation should include a range of community based facilities including group homes, training and occupational centres and support personnel; residential assessment and treatment units offering differing degrees of security; rehabilitation and aftercare.
PREVENTION

The scope for prevention of mental illness and behavioural problems is considerable.

Family Psychodynamics

The adjustment made by a family with a child with mental retardation has a profound effect upon the future life and mental health/well being of the mentally retarded person. The majority of families make a satisfactory adjustment, but faulty adjustment is a common antecedent of behavioural and other problems.

Psychiatric help is rarely sought until problems are well entrenched. There is considerable scope for the early identification of families at risk and subsequent effective intervention.

Life Events

People with mental retardation are as, if not more, vulnerable to life events as the general population and may react with a variety of mental health problems. There has been a failure to appreciate this in the past. The loss of the last caring relative in midlife can be particularly devastating and have profound consequences for the client’s future life style.

Anticipation and careful preparation for these events and bereavement counselling, if necessary, can avoid much distress and morbidity.

Factors in behaviour disorders

Behaviour disturbance may be the manifestation of impaired communication skills, sensory deficits, organic brain damage or mental illness.

Early identification and the correction or amelioration of communication and sensory impairments, accurate diagnosis and prompt treatment of underlying mental illness and management advice to parents and carers can significantly reduce morbidity.

Stress and Community Care

Poorly organised community care schemes can place undue stress on the individual. They may offer victimisation, financial and health worries and lone-line with consequent psychiatric morbidity. Great care is needed in assessing the level of support required by an individual person in community care.

Staff Training

The early detection and aggressive treatment of mental illness in people with mental retardation is essential if morbidity is to be reduced. This requires that front line professionals, particularly care staff and families, are adequately trained in the recognition of signs suggestive of mental disorder and know where to obtain help.

Treatable psychiatric illness still goes undetected in people with mental retardation. The elderly and those with severe mental retardation are particularly at risk.
LEGAL AND ETHICAL ISSUES

The General Assembly of the United Nations constructed the Declaration on the Rights of Mentally Retarded Persons in 1972. This declaration stated that the mentally retarded person has the same rights as other human beings, including the right to proper medical care, an inherent right to respect for their human dignity and the same civil rights as other human beings. Disabled persons shall be able to avail themselves to qualified legal aid when such aid proves indispensable for the protection of their persons.

What is the importance of Normalisation in this context?

The normalisation philosophy originated in Scandinavia in the 1960s and has led to the de-institutionalisation of services. One of the main aims was to provide for people with mental retardation as ordinary life as possible. The implementation of this philosophy requires provision of the support necessary for the individual to realise this aim. How far the aim is realised depends on the staff who are employed and carers including family members to carry out that support. The very fact that a person with mental retardation and mental health needs is in receipt of services puts them in a position where they are dependent on the values and attitudes of those around them. This is the reason why it is so important for staff and carers to spend time examining their own attitudes, and for organisations to formalise a code of ethics to safeguard people's rights.

What are the general principles underpinning legal and ethical issues for people with mental retardation?

People with mental retardation have the same rights and responsibilities as everyone else. Much of the law relating to people with mental retardation is general law which applies to everyone. Specific legislation has been enacted in most countries to cover sexual abuse and other forms of exploitation, protection of property, treatment of mental illness and conviction and disposal following criminal offences. In most countries parents can exercise certain rights on behalf of their children. For adults - i.e., eighteen, and in some cases from sixteen, depending on the national laws these parental rights cease.

Problems arise for people with mental retardation not because they do not have rights, but because they may not have the ability to express or exercise those rights, or because others may be disinclined to recognise those rights.

Can people with mental retardation give consent?

The consent process for people with mental retardation must not be thought of as homogeneous. The problem is that the term mental retardation covers a wide range of intellectual abilities from mild to profound. Some generalisations may provide useful guidelines. There is a grey area in the law, in some countries, for the adult (18+) who cannot give consent. Parents cannot give consent on their behalf, although it is good practice to have their agreement. Many people with mild mental retardation can give consent and those with moderate mental retardation can give consent if the choice is simple. Those with severe mental retardation cannot give consent.
Where consent cannot be given, the matter may need to go to court. In the special cases of sterilisation, abortion and organ donation, the courts must make a ruling for the individual. Other countries extend parental rights or employ a guardianship system.

**Can the competence of people with mental retardation be improved?**

Legal competence can be improved in many people with mental retardation. People with mental retardation require encouragement to be more autonomous. Consideration must be given to the opportunities that the individual has had for learning to make choices in life, and what consequential results have been experienced. It can be difficult to get away from a paternalistic system. One has to consider the risks involved in allowing the client to make a choice.

People with mental retardation need to learn to make choices from an early age, and need help to experience the consequences of decisions. Parents, care workers and the medical profession must understand the legal situation, yet, at the same time, the person with mental retardation needs to feel included in the decision-making process.

It is very important to value people with mental retardation and, where decisions are made on their behalf, those decisions should be made with honesty, respect and humility.

**Can people with mental retardation make decisions?**

The overwhelming message should be that people with mental retardation are people first. Even where mental health issues exist, principles of citizen’s rights should take priority over protection principles for the individual. However, where behaviour problems, challenging behaviour or psychiatric illness are present, there are additional considerations regarding the protection of others in the wider environment. Risk-taking decisions must be considered by a systematic procedure that weighs up the relative benefits, costs and safeguards required in potentially risky situations.

When a decision to take a risk is made, a plan of implementation and safeguards should be drawn up which will include how progress will be monitored and by whom. Being explicit about costs and benefits to the individual should improve the quality of decision-making and produce judgements that are more ethical.

**Police questioning of people with mental retardation**

There is a Code of Practice for police in the UK and in some other countries to follow for people with mental retardation. If the police suspect that someone has mental retardation, they cannot interview that person except in the presence of an appropriate adult, who may be a social worker, relative or any responsible adult who is not employed by the police.

**What is Advocacy for people with mental retardation?**

Advocacy is about being able to make personal choices. A person with mental retardation and mental health needs should be given the opportunity to assert their own point of view based on their preferences, wishes and feelings. An independent advocate for a person with mental retardation can help the individual to express his or her personal concerns and aspirations, and find ways to understand, respond and represent that person’s interests as if they were their own.
SEXUALITY AND PEOPLE WITH MENTAL RETARDATION

Historically, the sexuality of people with mental retardation was dealt with by segregation. Long-stay asylums were built to house people away from society at large and to prevent sexual relationships and reproduction. Men and women were accommodated separately in all-male and all-female wards. The assumptions were that people with mental retardation were either "child-like" and therefore lacking in sexual feelings, or "uncivilised" and therefore unable to control their impulses.

In the last 20 years, the move to "value" individuals with mental retardation as members of society has led to a widespread acceptance of their right to an adult sexual identity. The United Nations in 1971 spelled out people's rights to receive training in social-sexual behaviour, the right to knowledge and the right to express sexual impulses in the same forms that are socially acceptable for others.

There is a need to look at how one perceives a person with mental retardation and mental health needs in terms of their sexuality. It is often said of people with mental retardation that they have "no interest in sex". This is a statement that must be questioned as it could well stem from a remnant of the "childlike" model for understanding people with mental retardation.

Could the behaviour of people with mental retardation be related to their sexuality?

It is not uncommon for forms of challenging behaviour to appear sexually motivated because the individual has learnt that sexually inappropriate behaviour produces the response that he or she is seeking. The staff response could be attention, distress or avoidance of that individual. Again, how one understands the message is crucial and may be based on our own biases. The message can be interpreted as "illness", challenge, sexual attraction, a need for affection, or a random illogical, unpredictable urge.

How staff and carers feel about people with mental retardation expressing themselves sexually is very influential in the self-concept of individuals and how they view their own sexuality. Not acknowledging someone's sexual needs may reduce problems for staff and carers, but will be damaging to the individual's personal growth, and infringe their rights.

Sexual Abuse

While people with mental retardation have a right to express their sexuality, they have a complementary right to be protected from sexual abuse and exploitation. This right is reinforced by criminal law on rape, assault and consent. All staff and carers should be aware that they have a duty to report an allegation of sexual abuse, and this obligation over-rides their duty to keep a confidence. People with mental retardation and mental health needs are more at risk of sexual abuse than most other members of the society.
SELECTED READING LIST

- Mental Health in Learning Disabilities Training Package
  N. Bouras and G. Holt (Eds.) (1997)
  Pavilion Publishing. ISSIN: 1 900 600 41 2

- Mental Health in Learning Disabilities Handbook
  G. Holt and N. Bouras (Eds.) (1997)
  Pavilion Publishing. ISSIN: 1 900 600 46 3

- Mental Health in Mental Retardation
  N. Bouras (ed.) (1994)
  Cambridge University Press. ISSIN: 0-521 43495 5

- Psychiatric and Behavioural Disorders in Developmental Disabilities and Mental Retardation
  N. Bouras (ed.) (1999)
  Cambridge University Press. ISSIN: 0-521 64395-3

- Psychiatry of Learning Disabilities
  O. Russell (ed.) (1997)
  Gaskell ISSIN: 1 901242 02 1

- Developmental Neuropsychiatry
  J. Harris (1995)
  Oxford University Press. ISSIN: 0 19 509849-8

- Handbook of Treatment of Mental Illness and Behaviour Disorders in Children and Adolescents with Mental Retardation
American Psychiatric Press (in press)
INTERNATIONAL ORGANIZATIONS

- World Psychiatric Association, Section of Mental Retardation
  Nick Bouras, Chairman

- Mental Health in Learning Disabilities Centre, York Clinic, Guy's Hospital
  London SE1 3RR - UK

- European Association Mental Health in Mental Retardation
  Anton Dosen MD, President
  Nieuw Spraeland Wanssumseweg 14 - Oostrum Postbus 5029 5800 GA Venray The Netherlands

- National Association for People with Dual Diagnosis (NADD)
  Robert Fletcher PhD, Executive Director
  132 Fair Street, Kingston NY 12401 - 4802 USA

- International Association for the Scientific Study of Intellectual Disability
  IASSID Secretariat c/o
  Philadelphia Services Foundation PO Box 505 8070 AM Nunspeet The Netherlands