

MENTAL HEALTH AND INTELLECTUAL DISABILITIES

ADDRESSING THE MENTAL HEALTH NEEDS OF PEOPLE

WITH INTELLECTUAL DISABILITIES

Report by the Mental Health Special Interest Research Group of the
International Association for the Scientific Study of Intellectual Disabilities
to the World Health Organisation

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TABLE OF CONTENTS

	Page Numbers
1. Summary	3
2. Introduction and Terms of Reference	4
3. Definitions and Classification	5
4. Historical Background	8
5. Epidemiology	11
6. Intellectual Disability, Mental Health and Challenging Behaviour	13
7. The Prevention and Detection of Mental Ill-health and its Treatment	15
8. Services	22
9. Offending and the Criminal Justice System	24
10. Ethical Considerations and Issues of Consent	27
11. Research	29
12. Acknowledgements	31
13. References	32
14. Figure 1.	35

1.0 Summary

1.1 People with intellectual disabilities have a high risk of developing additional mental health problems that can go unrecognised and have a major effect on general well-being, personal independence, productivity, and quality of life, as well as impacting on family and other carers. The combination of intellectual disabilities and mental ill-health can also give rise to stigmatisation and prejudices that lead to social exclusion. The report considers the relationship between intellectual disability, ‘mental ill-health’ and behaviour disorders or behaviour problems, and focuses on the maintenance of mental health, the prevention of mental and behaviour disorders or behaviour problems and the assessment, diagnosis, and management of mental disorder, behaviour disorders, or behaviour problems **as** these co-occur with developmental intellectual disability.

1.2 People with intellectual disabilities (ID) are a highly diverse group with significant variations in the extent and nature of their intellectual impairments and functional disabilities, the presence of related sensory and physical disabilities, and in their social and family backgrounds. Thus, emotional difficulties and acute or persistent mental disorders can present in both typical and atypical ways. A partnership is required between those providing for the continuing support of people with intellectual disabilities and those with specialist health expertise that can address developmental, biological, psychological, and social factors that may predispose to, precipitate, or maintain the presence of mental or behaviour disorders. Such partnerships should ensure that skilled social support is available to people with intellectual disabilities in order to enhance mental health, minimise risk of occurrence of behaviour problems, and ensure that, if such problems arise, they are taken seriously and effective and ethical treatment and supportive strategies are made available.

1.3 This report also considers the involvement of service systems when people with intellectual disability are suspected or convicted of offending, the legal and ethical framework within which healthcare and other important decisions can be made on behalf of people who do not have the capacity to make the decisions for themselves, and the need for further research.

2.0 Introduction and Terms of Reference.

2.1 This report has been prepared by the Mental Health Special Interest Research Group (MH-SIRG) at the invitation of the International Association for the Scientific Study of Intellectual Disabilities (IASSID), a non-governmental organisation associated with the World Health Organisation (WHO). The MH-SIRG was inaugurated at the IASSID meeting in Helsinki in 1996 and held meetings in Cambridge, UK, in 1998, and in London, in conjunction with the European Association on Mental Health and Mental Retardation, in 1999, and in at the IASSID meeting in Seattle, in 2000.

2.2 This report defines terms related to professional and support services for people with co-occurring mental disorders and intellectual disabilities and outlines key issues with respect to the epidemiology, aetiology, and treatment of mental and behaviour disorders, as they affect people with intellectual disabilities, thereby highlighting health and social policy and practices that would enable the best possible mental health for people with intellectual disabilities. The broad themes of the report are therefore the maintenance of mental health, the recognition of mental and behaviour disorders, and related treatment.

2.3 In the paper we also include consideration of behaviour problems, in some instances referred to as challenging behaviour, in that the occurrence of such behaviour indicates the need for appropriate assessments with a view to identifying relevant aetiological factors that inform intervention. Such behaviour may or may not be due to an underlying mental illness. What is important is to identify the developmental, social, psychological, and biological factors that predisposing to mental disorders, behaviour disorders, or behaviour problems, as well as precipitating and maintaining such problems, thereby informing preventative, treatment and management strategies.

2.4 There are marked variations across nations and between cultures with respect to attitudes toward and opportunities available to people with intellectual disabilities. The same is true for those who have experienced serious mental health problems. Thus, for affected individuals, the presence of co-occurring intellectual disabilities and mental disorders has the potential to increase social exclusion, stigma and neglect due to misconceptions, misunderstandings, prejudices, and historical practices within different societies and cultures. This report

attempts to minimise such misconceptions and thereby enhance the likelihood that people with intellectual disability who develop serious mental health problems or present with behaviour problems, receive timely, appropriate, and effective help.

3.0 Definitions and Classification

3.1 The term intellectual disability is synonymous with other terms that have been used historically to describe individual generalised delays in development and difficulties in achieving independence, such as mental retardation and mental handicap. The term ‘intellectual disability’ used in this context refers to the presence of delayed early developmental milestones and associated delay in intellectual and functional development, such that a person's capability for self-determination and independent functioning is likely to be significantly lower than that of the average person during their lifetime.

3.2 Increasing emphasis has also been placed on the concept that the definition of disability is a ‘dynamic’ one and reflects social opportunities and attitudes, in addition to the functional and personality characteristics of the person concerned. With this in mind people with intellectual disabilities has been defined as those whose ability to understand, evaluate and to communicate information and to respond adaptively to events or situations is, or is perceived to be impaired, such that accommodation is required on the part of others. This interactive model of disability is important as it stresses the responsibility of society to accommodate to the needs of others, and also how changes in self-esteem, personality characteristics, and mental ill-health can contribute to a person’s overall functional impairments.

3.3 The reasons for significant developmental impairments are multiple and include the presence of chromosome abnormalities, single gene disorders, environmental factors, such as perinatal trauma or intra-uterine infections (e.g., maternal rubella), maternal and early childhood nutritional deficits (e.g., iodine deficiency), maternal alcohol abuse, or severe childhood neglect and deprivation. There also remain as yet many unidentified causes. The presence of mild intellectual disability rarely has a single identifiable cause, but is a consequence of both polygenic and social/environmental influences. The extent to which particular causes predominate in any country varies depending on the social, political and economic status of the country, and the resultant health and nutritional status of the general population, particularly that of the mothers and newborn children in the poorest families.

Equality of access to educational, social and health resources are therefore important factors in minimising mild intellectual disability, particularly in western countries. Concerns regarding the quality of general population health and social care are highly relevant because intellectual disability occurs in all countries and among all social and economic strata of the population.

3.4 This term intellectual disability therefore refers to a very heterogeneous group of people. Some have genetically determined disorders that have a marked effect on brain development and therefore on intellectual, social, and functional abilities. Others may develop adequate living skills, are able to make their needs and wishes known through spoken language, and lead relatively independent lives, but have poor psychological resources and also are often disadvantaged in society. Some sensory, physical, or developmental disabilities such as cerebral palsy or autism spectrum disorders (such as autism, or pervasive developmental disorder - PDD) are often considered to be related to intellectual disability, in that many individuals with these other conditions also have evidence of significant intellectual disability. The mental health needs of this heterogeneous group of people are therefore varied and complex, and mental and behaviour disorders can present in both typical and atypical ways, often depending on the communication skills, in particular, verbal skills, of the person concerned.

3.5 The term mental health is not easy to define. It consists of more than the absence of mental disorder. It is a state of mental well-being that, together with other factors, enables children and adults to attain independence, be productive, and participate in personally fulfilling ways in society. Whilst periods of sadness, anxiety or general distress are part of life, sound mental health ensures that a person has the emotional resources, often with the support of others, to manage life-stresses and thereby prevent serious and prolonged effects on general functional abilities. The term mental ill-health is also used in this paper to refer to a lack of mental well-being. This may include very diverse states of emotional distress that may vary in their manifestations across cultures and, for example, may be due to the presence of a specific mental or behaviour disorder, such as severe depression or self-injurious behaviour, or which might follow bereavement.

3.6 The terms mental disorder or psychiatric disorder are synonymous and refer to a collection of symptoms (or behaviours) that are characteristic of specific disorders of mental

health. These are defined in recent versions of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV--American Psychiatric Association, 1994) and the mental disorders section of the International Classification of Diseases (ICD-10, World Health Organisation, 2000). The diagnosis of specific mental disorders implies some understanding as to aetiology, and a distinguishable composite of affective, behaviour, and cognitive characteristics, and provides a guide to empirically validated and likely effective treatment strategies.

3.7 The term mental illness refers to a subset of biopsychosocial conditions that are acquired during life and include severe psychotic disorders (e.g., schizophrenia), affective illnesses (e.g., bipolar disorders) and organic disorders such as senile dementia of the Alzheimer type. Other mental disorders include, for example, generalised and specific anxiety states (including phobic disorders) and obsessive compulsive disorders. In childhood, and to a lesser extent in adulthood, there are the specific problems of conduct disorder (sometimes associated with personality disorder, later in adult life), emotional disorders and Attention Deficit Hyperactivity Disorder (ADHD).

3.8 Terms such as maladaptive, problem, aberrant, or challenging behaviour or behaviour disorders or problems have been commonly used to describe a range of behaviours (e.g., aggression, self-injury, smearing, severe stereotyped behaviours). These terms are generally descriptive and do not necessarily in themselves imply any understanding as to cause. For example the basis of self-injurious behaviour is likely to be different in those people with Lesch Nyhan syndrome, than those with autism, or the skin picking associated with Prader Willi syndrome. . The severity may be such that their occurrence may threaten the person's physical health, or have a marked effect on the person's quality of life and opportunities as well as that of family members and other caregivers providing support. Such behaviour may be indicative of impoverished opportunities in the person's life, may have been shaped through a failure to recognise the role such behaviours can play in communicating need, may have arisen and been maintained by adventitious environmental factors, or may be due to the presence of an additional mental disorder or physical illness. There are many possible developmental, biological, social, or psychological factors that interact and influence the occurrence of such behaviours. In an individual case several factors, and their conjoint influences, may be relevant to the onset or persistence of a behaviour (Matson, 1985).

4.0 Historical Background

4.1 In many nations the 20th century brought dramatic healthcare and lifestyle changes for general populations, and especially to the lives of people with intellectual disabilities, and in professional understanding of causation and the factors that contribute to individual development and to quality of life. In western countries early in the century the notions of the Eugenics Movement resulted in the isolation of people with intellectual disabilities in institutional settings. Practices that would now be considered unacceptable, contravening the United Nations Convention on Human Rights, such as sterilisation without consent, were common in many nations. In the second half of the century, there was a radical change in the philosophy underpinning support of people with intellectual disabilities and the widespread adoption of the principles of 'normalisation' in health and social services, leading to changes in attitudes and models of support (Wolfensberger, 1969). Living in appropriate community settings, for example, ordinary quarters, has become recognised as a fundamental right of all people with intellectual disabilities, as it is for the whole population. The extent to which this has been achieved varies within and between countries and is largely dependent on the commitment of local and national organisations and the availability of the necessary resources, including specialised mental health and behavioural services to address issues that might otherwise lead to institutional placement. Thus, in some western countries inadequate institutional care continues, and in others there is an acknowledgement in principle of the need for community-based care but varying development of the necessary services and supports network. Both among states or provinces within western countries and among westernised nations, there are indications that social policy affecting development of supports for people with intellectual disabilities is related generally to per capita fiscal resources available for educational, health, and social services as a whole. In developing countries, often because of more pronounced and competing demands on health resources, few services are available for people with intellectual disabilities and their families.

4.2 Advances in the biological and biobehavioural sciences in the latter part of the 20th century led to the identification of the aetiology of some groups of people with intellectual disability that had in common specific physical characteristics, such as Down syndrome. Increasingly, specific chromosomal, single gene and environmental causes, resulting in the presence of intellectual disability in childhood and adult life, have been identified (Alexander, 1998; Baumeister, Kupstas, & Klindworth, 1991; Dykens, 2000). In some cases

there are direct implications for prevention, such as when the cause relates to nutritional deficiencies or intra-uterine infections or toxic exposures. More recently, potential relationships between specific syndromes and particular patterns of development or behaviour or an increased propensity to psychiatric disorder are being recognised – referred to as behavioural phenotypes (State, King, & Dykens, 1997). Examples include the characteristic behavioural and neuropsychological profiles of people with autistic spectrum disorders, severe self-injurious behaviour associated with Lesch-Nyhan syndrome, risk of Alzheimer disease in people with Down syndrome, a particular cognitive and language profile observed in people with Williams syndrome, and severe over-eating behaviour of people with Prader-Willi syndrome.

4.3 The last century also saw marked changes in the understanding of acquired mental disorders. The features of severe psychotic disorders, such as those of dementia praecox (schizophrenia), were initially characterised and the aetiology seen as biological. There then followed a radical re-conceptualisation of such conditions as having a social and family-based causation. These models were inadequate and twin, family, and adoption studies in the latter part of the century showed that the vulnerability to the majority of major mental illnesses was, at least, partly genetically and biologically determined (e.g., Pauls, Morton, & Egeland, 1992). The development of more refined diagnostic criteria and the integration of biological, psychological, and behavioural science, and social models have since enabled discernment of more definitive aetiologies of major mental illnesses to be constructed. Genetic and other biological vulnerabilities, early childhood and present life experiences, and events which may reduce available psychological resources (e.g., such parental loss, abuse, social exclusion), and limited social networks and support may all be important when considering why some people develop severe mental health problems at particular times in their lives and in determining subsequent prognosis and response to treatment (Szymanski & King, 1999).

4.4 For many mental disorders new treatments have been developed including, for example, effective medications and psychological and behavioural treatments for severe mental disorders, such as schizophrenia and bipolar mood disorders, and for other disabling conditions such as anxiety and obsessive-compulsive disorders. In the majority of western countries, long-stay institutions for people with serious mental illnesses were considered

unnecessary and have largely been closed. However, a failure to recognise the limitations of medication and of the importance of appropriate social support and community services led, in western countries, to some people with severe and persistent mental disorders becoming homeless and destitute.

4.5 Although in the early 20th century the German term ‘pfpopf-schizophrenie’ had been used to describe the co-existence of schizophrenia and intellectual disability, the relationship between intellectual disability and disorders of mental health have only relatively recently received proper attention. This was partly because of confusion regarding use and definition of terminology. Intellectual disability is defined in most cultures as a mental disorder (e.g., as mental retardation in both ICD-10 and DSM-IV) and there was a failure to recognise that comorbid mental disorders may also occur. Thus, the symptomatology of depression, for example, was considered to be due to that person’s intellectual disability. This has been referred to as ‘diagnostic over-shadowing’. As well, for many years practitioners and researchers assumed that many mental disorders, especially those that were assumed not to occur among children, did not occur among people with mild or severe intellectual disabilities. These factors, combined with problems establishing diagnoses, led to a failure to recognise that some people with intellectual disabilities can and do manifest acquired mental disorders. Multi-axial systems of classification have helped to resolve this with a separation of developmental disorders, such as intellectual disability (mental retardation) and personality disorders (Axis II), from acquired clinical disorders (Axis I). Organisations such as the National Association for the Dually Diagnosed in the USA were founded to promote this understanding.

4.6 Key Points

- **Although intellectual disability is considered a ‘mental disorder’ (i.e., mental retardation), a clear distinction needs to be drawn between this disorder of development and acquired mental conditions, such as severe and persistent mental and behaviour disorders.**
- **During the 20th century there have been radical changes in the way in which people with either intellectual disability or severe mental disorders are supported, and in**

the development of new treatments. Appropriate social care services are central to any strategy for supporting people with serious mental ill-health or intellectual disabilities, particularly people with both intellectual disabilities and severe and persistent mental disorders.

5.0 Epidemiology

5.1 Answering the question as to what extent the population of people with intellectual disabilities manifests mental or behaviour disorders has proven to be methodologically difficult. First, the definition of intellectual disability is imprecise and whilst measures of intellectual ability can be a guide, there may be uncertainty whether someone should or should not be considered to meet the criteria. This is particularly so when a person's cognitive functioning is superficially average but social functioning is markedly impaired and limits social acceptance, or when a person's cognitive function appears mildly impaired but impairments of social functioning are not apparent. Secondly, whilst identification of all children with an intellectual disability may be possible when they are receiving statutory education, identification of all adults is more difficult and therefore most studies only include those people with intellectual disabilities known to services (i.e., an administrative sample). People with additional needs, such as people with both intellectual disabilities and mental or behaviour disorders, are likely to be over-represented in this group. Thirdly, diagnosis of mental disorder relies heavily on the ability of a person to describe his or her own mental experiences and feelings. For some people with intellectual disabilities this is not possible and mental states may have to be inferred from observations by family members or other carers. Fourthly, use of diagnostic criteria for different mental disorders entails determining the presence or not of specific mental experiences. These criteria may need some modification but if they are broadened too much they may no longer be valid (Sovner & Hurley, 1986). Finally, different terminology and diagnostic criteria have been used across studies and direct comparisons between studies may not be possible. For example, whether behaviour disorder is included as a mental disorder radically changes the perspective of any study.

5.2 Despite these methodological issues in research, there is adequate evidence that people with intellectual disabilities do experience high rates of the full range of mental disorders (Bregman, 1991; Holland, 1999). Studies undertaken in Australia, Europe, and the USA

using varied methodologies have arrived at broadly similar results. There is a general consensus that rates of mental disorder (including behaviour disorders) are high, with a prevalence of nearly 50% in people with severe or profound intellectual disabilities, and about 20% to 25% in people with milder intellectual disabilities (see Rutter et al, 1970, Birch et al, 1970, Jacobson, 1982, Borthwick-Duffy, 1994, Tonge et al, 1996). Overall prevalence rates of 'behaviour disorders' may be as high as 20% and occurring more commonly among people with severe intellectual disabilities and in particular, among those meeting criteria for autistic spectrum disorders and those with sensory impairments, the occurrence being somewhat lower among people who have severe motor or mobility limitations. People with specific syndromes may also have high rates of specific 'behaviours'. For example, self-injurious behaviour in Lesch Nyhan syndrome, severe over-eating, temper tantrums, skin picking and obsessional behaviours in Prader Willi syndrome. The presence of such problems is the single most important cause of social care breakdown in community living, disruption of productive vocational or pre-vocational involvement, admissions to long stay hospitals, and carer stress.

5.3 Research studies have used different approaches to establish the extent to which specific mental disorders affect people with intellectual disabilities. In larger samples based on service registries, varying criteria have been used by practitioners in different localities that are then aggregated. Smaller samples may be biased with respect to methods of case inclusion. The above methodological problems make such studies problematic. Another central question is whether the same diagnostic criteria should be used as for the general population, or whether they should be modified and, if so, for whom, how, and to what extent. This remains an unanswered question. In the case of the illness schizophrenia, which is a disorder of thinking, perception and language, it is unlikely that those who have never acquired language, because of their profound abnormality of brain development, can develop this illness. However, it is unknown whether there may be an equivalent clinical syndrome with similar aetiology that would be responsive to the same treatment. People whose impaired spoken language is due to pre-lingual deafness (e.g., with Usher syndrome) or to severe dysarthria (e.g., with cerebral palsy) clearly can suffer from psychotic disorders (Hess-Roever et al, 1999). Studies that have investigated the rates of schizophrenia among adults with intellectual disabilities have generally found a lifetime prevalence of 3%, compared to 1% in the general population. There are few studies of rates of depression or bipolar mood disorder in properly ascertained community samples although there are indications that

people with specific syndromes may be at increased risk (e.g., people with Down syndrome, Collacott et al, 1992). Among people with autism spectrum disorders and some specific syndromes (e.g., Prader-Willi syndrome), obsessive compulsive behaviours are common, but whether they are best conceptualised as an acquired disorder or as a feature of an abnormal or delayed pattern of neurological and behavioural development, remains uncertain.

6.0 Intellectual Disability, Mental Health and Challenging Behaviour

6.1 The epidemiological evidence above indicates that the full range of acquired mental disorders can be found affecting people with intellectual disabilities. In this section the potential relationships between the presence of an intellectual disability and the occurrence of a mental or behaviour disorder is considered. These high prevalence rates indicate that an intellectual disability is, in itself, a risk factor for the development of both mental ill-health and behaviour disorder. The mechanisms that link the presence of intellectual disability and this increased vulnerability, however, are less clear. Potential mechanisms are best conceptualised by considering, from a developmental perspective, biological, psychological, and social factors and their respective roles in predisposing to, precipitating, or maintaining the presence of an acquired mental or behaviour disorder. Whilst the research evidence is limited such a model provides a useful framework for the consideration of aetiology, prevention and treatment of mental-ill health and problem behaviours.

6.2 Biological factors: There are different strands of evidence supporting the view that impairment of brain function, which is highly likely to be present in people with intellectual disability, may itself increase the vulnerability to mental ill-health. First, there is evidence that the vulnerability to major mental illnesses, such as schizophrenia, may not only relate to genetic factors but also to the presence of pre-existing brain abnormality (e.g., the neurodevelopmental theory of schizophrenia - Gilmore, Sikich, & Lieberman, 1997). Secondly, there is the observation that people with intellectual disabilities due to specific syndromes may have particular patterns of development and specific vulnerabilities (behavioural phenotypes). Thirdly, some biological factors may explain the onset of mental disorders. For example severe epilepsy, which is common in people with intellectual disabilities, if specifically originating from the temporal lobes of the brain, may be associated with psychotic-like behaviour or mood disorders (Belov & Kazakovtsev, 1989). This association is rare in the general population but the extent it may be of relevance in those

with more severe abnormalities of brain functioning and associated intellectual disabilities is unknown. Fourthly, where brain development is severely arrested, there may be a pattern of behaviour that reflects the level of development and coping skills of that person, irrespective of his or her chronological age, for example, the continuation of incidental self-stimulatory or repetitive movements, severe temper outbursts, or of checking behaviours characteristic of normal early childhood.

6.3 Behavioural and psychological factors: There are two main strands to this perspective. The first relates to a substantial body of work based on principles of applied behaviour analysis which supports the view that particular behaviours may be shaped and learned, and acquire functional relationships with environmental or social events that may be interpreted by observers as a form of communication. Thus, for example, aggressive or self-injurious behaviour may be reinforced through the response of others in the environment and its occurrence affected by different setting events and environmental contingencies (e.g., the behaviour may be instrumental in escaping or avoiding certain tasks - Taylor & Romanczyk, 1994). The same may also be true for anxiety and other mental states. From this perspective, such behaviour (and also mental states) is not conceptualised as a mental disorder but rather the result of a naturally occurring process, whereby specific behaviours are inadvertently shaped over time. More recently these models have been elaborated further and the significance of specific developmental disorders, such as those in the autism spectrum and different biological states or mental ill-health, have been recognised as important contributory variables. Interaction between factors that are predominately cognitive, affective, or developmental in nature and environmental contingencies are likely to be common, and although these relationships are complex and not well understood, these interactions influence the behavioural expression of mental disorders (Levitas & Gilson 1994). A second body of work relates to the consequences of having an intellectual disability in terms of functioning effectively in a cognitively complex and demanding society and also to the limited opportunities for a satisfying and productive lifestyle that may be available to people with intellectual disabilities. Here the mediating mechanisms may include reinforcement of feelings of worthlessness through the impact of negative life experiences, lack of emotional support, and limited life opportunities (Donaldson & Menolascino, 1977).

6.4 Social Factors: In most cultures the importance of family life, and other cultural equivalents, an appropriate living environment, social networks, meaningful employment,

and the right to privacy are taken for granted. The social milieu in which people live constitutes an important contribution to resilience and the development of practical, social, and coping skills that may provide protection against the development of mental ill-health. The quality of social care and employment or occupational opportunities commensurate with individual abilities, and, most importantly, freedom from exploitation and abuse, are prerequisites for enhancing mental health and minimising the occurrence of behaviour disorders, as it would be for any group of people. In addition, for people with impaired understanding and expressive communication, the use of augmented forms of communication, such as signing and objects of reference are also important to maximise instrumental use of the environment, to communicate needs and wishes, and to help make life more meaningful and predictable. There is also the potential in many societies, due to historical and sometimes persisting customs and mores, for social exclusion of people with intellectual disabilities, compounded by discriminatory attitudes and practices, including those relating to gender, ethnicity, and socio-economic status (e.g., Azmi et al, 1997). The lack of resources, the continuation of institutional models of social care, and the occurrence of psychological, physical and sexual abuse all remain important issues.

6.5 Implications for Policy and Practice

- **The occurrence of behaviour disorder or mental ill-health is best conceptualised as the outcome of complex interactions between developmental, biological, psychological, and socially determined risk and protective factors.**
- **Positive mental health, reflected in resilience, and social and coping skills, is necessary in order to enhance the chances that an individual with intellectual disabilities is able to participate fully in society in personally productive and satisfying ways.**

7.0 The Prevention and Detection of Mental Ill-Health and its Treatment.

7.1 General Principles: This report has emphasised the considerable variability in independence and functioning among people with intellectual disabilities, including those with biologically determined disorders of brain development and associated severe

intellectual disabilities, and other people with milder intellectual disabilities, who have often already experienced social, educational, or economic disadvantage and the related consequences of these conditions. It is therefore difficult to generalise across this group; it is likely that a diverse range of factors will contribute to mental ill-health. Although there has been considerable research regarding behaviour disorders, there has been a marked lack of research investigating the vulnerabilities that contribute to mental ill-health among people with intellectual disabilities. However, it is likely that such research would identify parallels to findings regarding protective or preventative factors that increase resilience to the psychosocial impacts of adverse effects within the general population (e.g., Rutter, 1999; Rutter, et al., 1997; Rutter & Sandberg, 1992). Figure 1 illustrates the range of factors that are important to the onset or alleviation of mental or behavioural disorders.

7.2 Early intervention: There have been very significant studies that have attempted to evaluate whether early interventions in childhood bring about more permanent change in adult life. It is outside the remit of this paper to review these studies in great depth, as they are not primarily concerned with mental health, although considerable research addresses risk factors for both intellectual disabilities and mental or behaviour disorders (Guralnick, 1997). A further complicating factor is again the heterogeneity of this group of people with intellectual disabilities. Whether findings from studies of early intervention involving, for example, children with specific syndromes, can be generalised to those with mild intellectual disabilities, is speculative. Early intervention for those very young identified at risk for specific behaviours (e.g., self-injury) may be of value. In general, some key principles can be identified from both intellectual disability and psychiatric research. These include: a) whilst children would appear to be resilient to adversity, childhood experiences, such as loss of a parent, sexual and physical abuse and neglect have longer term consequences on mental health and therefore, either their prevention or strategies to reduce their future impact, are important; b) behavioural interventions to reduce maladaptive behaviours or enhance social competence, associated with such disorders as autism spectrum disorders, are effective but results vary greatly among children with similar conditions and in some instances, management strategies have to continue in order that the benefits remain (Lonigan & Elbert, 1998; Surgeon General, 2000); c) in the case of disadvantaged children additional educational help is of value but the commitment of parents (or primary carer) is critical to the longer term success; and d) interventions in childhood that maximise and enhance instrumental and academic ability and social skills may reduce the likelihood of emotional problems and

mental ill-health in later life.

7.3 The Maintenance of Mental Health and Prevention of Mental Ill-health: Using the above framework, primary concerns relate to those factors that might predispose to mental ill-health. From a biological perspective these would include: a) the vulnerabilities that might be associated directly with having a specific syndrome or indirectly because of the general impairment in brain function; b) the person's physical health and the presence of other physical or sensory impairments; and c) the effective management of epilepsy when present. From psychological, behavioural, and social perspectives the key issues will vary according to individual circumstances and the degree of impairment and disability but include: a) an environment free from exploitation and abuse; b) the quality of the communication that enables individual wishes and needs to be understood and appropriately met; c) the nature of neuropsychological and other psychological and behavioural strengths and weaknesses; d) the extent of support to families and individuals that alleviates carer stress and enhances the quality of the home environment; e) relevant and effective educational opportunities and meaningful life opportunities that help maintain life satisfaction through the performance of valued roles (e.g., parent, partner, employee) albeit with supportive services; f) the availability of leisure opportunities and an appropriate social network; and g) the presence of non-discriminatory attitudes toward the person's specific disability or from beliefs about their gender, ethnicity, and culture.

7.4 Detection of Mental Ill-Health: The development, for example, of maladaptive behaviours, increasing withdrawal, or changes in a person's state of general well-being are all too often ignored and the fact that such change may be a marker for a possible mental health problem or early signs of a behaviour disorder may not be considered. It may be very difficult for people with intellectual disabilities to recognise themselves that they need help and they often depend on others to identify the potential significance of such changes. Thus, the key to the detection of potential mental ill-health is the acknowledgement that it can, and does, occur among people with intellectual disabilities. A second confounding factor is the belief that such problems are inevitable and unchangeable. This means that help is not sought. A third factor relates to the quality of assessments undertaken when help is sought. This is due to what has been described as 'diagnostic overshadowing' whereby someone's general mental state or behaviour is attributed to the fact that he or she has an intellectual disability (Reiss et al, 1982; White, et al., 1995). This diagnostic error has occurred for several reasons,

including the difficulty obtaining information from a person with limited or no language, the lack of good longitudinal data from informants demonstrating that there has been a change in mental or behavioural status, and lack of specialised training or experience among professionals. Consequently, psychiatric, psychological, or behavioural diagnostic identification often does not occur, and appropriate treatments and other interventions do not take place.

7.5 Assessment and Treatment: An important principle of assessment and case formulation is that it is a process with certain important components including: a) the initial recognition that a mental health problem may be present as described above; b) a period of data collection involving the person and one or more key informants, including information on the onset and course of any observed changes, the developmental, personal and medical history, as well as direct observation, mental state and physical examination and structured assessments and investigations invariably involving medical and allied health professionals; c) the development of possible hypotheses to explain the observations, including the diagnosis of any possible acquired mental disorder; and d) the synthesis of this information, frequently from different theoretical perspectives, to arrive at a formulation and treatment plan, which includes issues of consent.

7.6 Assessment Instruments: It is the process of assessment that determines the nature of any treatment and intervention. This may be aided by, or rely upon, the use of standard assessment measures and by accurate recording of behaviours or assessment of mental states. A distinction needs to be drawn between those assessment approaches that are a) essentially for the purpose of characterising the nature of any change in adaptive or maladaptive behaviour and b) those that have further potential explanatory value. The latter, such as diagnostic schedules or assessments of functional relationships among behaviours, have the potential to determine probable efficacious interventions because they are based on specific theoretical frameworks of established validity. These include structured interviews to determine mental state, such as the Present State Examination, or the Psychiatric Assessment Scale for Adults with a Developmental Disability (PAS-ADD). The diagnosis of depression, which might be determined by such an assessment, would lead to the use of, for example, antidepressant medication, and/or cognitive behaviour therapy, depending on the intellectual status of the person, because these have been found to be most effective (Hershfeld, 1994). In contrast, the descriptive scales, such as the Aberrant Behaviour Checklist, identify the

presence of particular behaviours (e.g., self-injury) but do not guide intervention. A further functional behavioural analysis may, for example, be required to establish the relationship of the self-injurious behaviour to the particular social and environmental circumstances of that particular person. Examples of such assessment instruments are given in the consensus statement published in the American Journal of Mental Retardation, (2000)

7.7 The complexity of the potential problems that arise invariably requires a multi- or interdisciplinary approach. Different disciplines apply their theoretical perspectives in attempting to arrive at a comprehensive understanding. Such assessments, when combined, lead to a comprehensive and informed understanding and thereby increase the opportunity for successful interventions. These may include interventions as diverse as changes in the social care environment, the development of social and living skills and opportunities, use of new methods to improve communication, different psychological and behavioural treatment strategies, and medication. In many instances, comprehensive assessment will indicate the need for interventions characterised by a combination of several of these strategies.

7.8 Diagnosis of Specific Mental Disorders: The complexity of the potential interactions of biological, psychological or behavioural, and social factors, together with the often associated impairment in language development makes the process of assessment, and thereby treatment selection, particularly problematic. In the general population much of the assessment and ultimate diagnosis of mental or behaviour disorder depends on obtaining a description of the person's mental experiences. Thus the diagnosis of psychotic illness will require evidence that the person has suffered from particular mental experiences characteristically associated with that disorder (e.g., third person auditory hallucinations, and passivity feelings in schizophrenia). For people with intellectual disabilities and spoken language such assessments may well be possible. For others, information from informants may be crucial and the presence or not of mental state abnormalities or characteristic biological features, determined indirectly. For example, disturbance of sleep and appetite, poor concentration, loss of interest, and agitation and distress may enable a diagnosis of depression to be made in the absence of a clear understanding of whether the person is actually feeling depressed (DC-LD Development Working Group, 2000).

7.9 Use of Psychotropic Medication: Whilst there is a substantive body of research that demonstrates the high rates at which psychotropic medications are used in both institutional

and community settings (usually over one-third of people are found to be prescribed psychotropic medication), these studies do not fully address the issue of treatment efficacy. It is not just whether people with intellectual disability are treated with psychotropic medication, but rather the rationale for its use, (i.e., what is it being used to treat) and whether that particular treatment of that specific disorder has been shown to be beneficial or not. It is the process of diagnosis and formulation that guides intervention. This process is often sadly lacking when the person involved has an intellectual disability, and as a consequence medication is prescribed to modify particular behaviours rather than to treat a mental disorder, such as depression or a psychotic illness. Anecdotal evidence suggests that psychotropic medication may be administered without consent to suppress behaviours that others do not like without any attempt to identify possible underlying causes (including mental illness), and without adequate provision for accompanying therapies or treatments. This might well amount to the abuse of people with intellectual disabilities. There is evidence that the risk of motor side-effects from neuroleptic medication is greater among those with pre-existing brain abnormalities, and that such medication has an adverse effect on cognitive functioning. Therefore the consequences of their improper use to treat people with intellectual disabilities are potentially very severe. As with all treatment the use of psychotropic medication is dependent upon the judgement that the benefit of such treatment will outweigh any disadvantages. The primary guide to treatment with psychotropic medication is the presence of a specific psychiatric disorder in which properly conducted trials have shown response to a particular medication (e.g., antidepressants for treating depression). There is, however, a need for further research to establish the place of medications, such as anti-convulsant and/or mood stabiliser medication (e.g., carbamazepine), selective serotonin re-uptake inhibitors (SSRIs), and the newer antipsychotic medications, as part of the treatment of 'target' behaviours, in the absence of a mental disorder. Moreover, substantive case-controlled research trials have generally not been conducted regarding treatment with past and new-generation psychotropic medication for people with moderate to profound intellectual disabilities, who often have evidence of specific neurological characteristics associated with the potential for further variation in medication response (National Institutes of Health, 1991). Whilst anecdotal evidence and limited trials have suggested some potential benefits from the use of the new generation medications, there has been no proper attempt to tease out underlying mechanisms. Whether, when improvements are noted, an acquired mental disorder was in fact present, which responded to treatment and resulted in a reduction in the prevalence of challenging behaviour,

has not been considered. It is likely that as the understanding of the potential contribution of brain dysfunction to such behaviour becomes clearer, the use of medications will become more informed and may be utilised in a more targeted manner as part of a range of treatment approaches. However, as in the general population, medication should almost never be the only approach.

7.10 Psychological treatments: there has also been an expansion in the development of psychological treatments either for the treatment of behaviour disorders, or for mental ill-health. The former are primarily based on applied behavioural analysis, and an understanding of the ‘function(s)’ of a particular behaviour. The latter include cognitive analytical and behavioural therapies, interpretative therapies and counselling, and skills based approaches such as social skills training and anger management. Whilst particular approaches (e.g., interpretative psychotherapy) may require some modification, and its use depend upon the level of language development of the person receiving the therapy, it is clear that psychological treatment approaches developed for the non-intellectual disabled may well be appropriate for those with intellectual disability. Similarly, support to families and/or other carers in the reduction of expressed emotion, and the presence of additional support prior to or after major life events may reduce the risk of relapse for those prone to psychiatric illnesses.

7.11 Implications for Policy and Practice

- **A range of appropriate service provision and expertise is required to meet the complex and often on-going health and social care needs of the significant proportion of people with intellectual disabilities who experience mental or behaviour disorders.**
- **Health and social care services have a responsibility to ensure that all those working in intellectual disability services understand how to help maintain positive mental health and minimise behavioural disruptions, through informed service provision.**
- **Effective management and treatment of mental ill-health and behaviour disorders and problems, require that there is an appropriate index of suspicion that mental**

disorders occur, and that thorough assessments are undertaken in order to inform intervention.

- **The treatment of mental ill-health and behaviour disorders must be based on a thorough assessment and formulation that may require, and often benefits from, the expertise of more than one discipline. Treatment interventions must be based on this formulation and the effects of any intervention must be reviewed regularly to inform future intervention and management strategies.**

8.0 Services

8.1 Economic and cultural differences within and between countries mean that the type and range of service provision will vary very considerably with different models of social and healthcare services. For example, the mental health sector in the USA is predominately private insurance based and shaped by managed care, whereas many European countries have significant state funded social and health care services. There are some direct parallels in intellectual disabilities in the USA to the European scene, in that the principal funding for services for people with intellectual disabilities is a federal health insurance program, which supports diverse not-for-profit services and federal funding also supports specialised diagnostic, treatment, and professional training centres. The situation in Australia appears similar in character to that in the USA, but services are very diverse among westernised nations as a whole (Jacobson, 1999). Among developing countries, such as those in Africa, the families or small, often religious, institutions, provide the care with limited or no additional support. The combination of high prevalence rates of psychiatric and behaviour disorders, complex health needs, and the specific difficulties with respect to language development that affect the manner in which mental ill-health presents and also impedes access to service, argues strongly for dedicated specialist and multidisciplinary community-based health support in partnership with individuals with intellectual disabilities, families, and providers of social and community care.

8.2 Personnel working in family support and community social care services must have the skills to manage services in a manner that help reduce risk factors and enhance protective factors that contribute to mental ill-health or behaviour disorders--as is illustrated in Figure 1. This requires the provision of informed support to families, the adequate training of support

staff, and managers of services committed to the provision of informed and quality services.

8.3 There should be ready access to good primary medical care, to health screening programmes available to the general population, and to specialist health and allied-health expertise. In the case of mental ill-health this should include the availability of people with those skills that are required to assess and treat such difficulties. This might include clinical psychologists, occupational therapists, psychiatrists, specialist nursing staff, speech and language therapists, and staff with specialist treatment expertise. Carers should have the ability to facilitate access to healthcare and, where necessary, aid health workers in obtaining relevant information as part of the assessment process. They should also have the ability to help the person with an intellectual disability to understand the nature of his or her difficulties and its implications.

8.4 For those people with intellectual disabilities who develop severe mental or behaviour disorders, there may be the need for admission to hospital or a speciality treatment centre, particularly if the severity of the condition is such that the person's health is significantly at risk or if he or she is at risk of suicide. Special care will need to be taken as the person concerned may be vulnerable to exploitation, injury, or abuse by other people residing in such settings. Hospital or centre admission should be for defined and positive reasons, and in the best interests of the person concerned, and discharge should be undertaken with appropriate levels of follow-up support, and should occur once the person is stabilised sufficiently that community or social care agencies can address his/her needs effectively. Special care needs to be taken for people who may temporarily have an impaired capacity to consent to such admission or to treatment. Different countries have different legislation to enable treatment for a mental disorder in the absence of consent when it is appropriate (see section 10). A robust appeals mechanism and a truly independent system of advocacy are of particular importance on these occasions.

8.5 The model of support that countries should aspire to requires adequate financial sources and the availability of a range of skilled support workers and health expertise. The extent to which this is available varies considerably, even in those countries with the strong economies. The support of people with disabilities has been recognised by the United Nations as a key responsibility for any responsible Government. The development of services requires a commitment to training and funding.

8.6 Implications for Policy and Practice

- **When planning services it must be recognised that people with intellectual disability are a diverse group who have in common early developmental delay and impairment in intellectual and adaptive functioning but who vary considerably in the nature and extent of their disability, its causation, their resources, and their social and family background.**
- **A range of social care provision, with varying levels of support, together with health and allied health expertise is required for services to be able to offer appropriate support, whether the person is living with their family or elsewhere in the community.**
- **A failure to provide services that can meet the needs of those people with additional mental problems or behaviour disorders will lead to placement breakdown, high levels of carer stress, and inappropriate therapy and sometimes abusive social care.**
- **A range of health and allied health expertise is required to meet the needs of this group of people, with staff able to work in different community settings that provide varying levels of support according to need. This requires a commitment on the behalf of Governments to the development of training programmes.**

9.0 Offending and the Criminal Justice System

9.1 People with below average intellectual abilities, including those who meet the full criteria for having an intellectual disability, have been found to be over-represented among those convicted of offences. This is a complex area of research because only a relatively small proportion of crimes result in conviction and therefore it is unknown whether people with intellectual disabilities in fact commit more crimes than others. Intuitively, it seems less likely that they would commit certain offences such as auto theft, embezzlement, or fraud. It has been claimed that people with intellectual disabilities may commit disproportionately more crimes of arson and of a sexual nature, but it is currently impossible to be certain

whether this is the case, or whether such observations reflect a higher arrest and conviction rate of people with intellectual disabilities (for any crime for which they are charged), as compared to people without intellectual disability. The majority of people with intellectual disabilities suspected or convicted of criminal offences have mild intellectual disabilities, and engage in property or acquisitive offences. Mental ill-health, drug and alcohol abuse, and homelessness are important predisposing factors (Winter et al, 1997). This group of people with a combination of a developmental disability, mental ill-health, and social difficulties are a classic example of the outcomes of social exclusion and neglect, and processes that perpetuate these personal and social circumstances.

9.2 Of serious concern is the fact that a person with an intellectual disability may face injustice when he or she becomes involved in the criminal justice process and may also be particularly vulnerable to abuse or neglect in prison. People with intellectual disabilities may not understand their legal rights, and false confessions, physical and sexual abuse when in custody, and the capital punishment of people with intellectual disabilities have all occurred in this context. Some may be diverted to long-term hospital care without having the facts heard and guilt established. Thus, special legal provision is required when a person with an intellectual disability is suspected or convicted of an offence. Such legal provision should aim to ensure that he or she is dealt with justly, and that his or her intellectual disability and the presence of any other mental health problem recognised. Personnel in the criminal justice agencies and specialist health and social care services must work together to support the person through the trial process and ensure that he or she receives appropriate help and that the person's rights under the judicial system are sustained. High quality legal expertise is essential.

9.3 Offending can be considered to be a form of behaviour disorder or consistent with a mental disorder (e.g., psychopathy or sociopathy), and a framework similar to that shown in Figure 1 is useful in this context. However, offending must not be seen as necessarily a 'psychiatric' disorder. Establishing guilt is a matter for the Court but specialist assessment can be crucial in informing the Court about the nature of the person's disability and other relevant matters that shed light on the offence committed (that is, if the person has been found guilty). The necessary assessments can be undertaken where the person lives but if the alleged offence is serious it may be necessary to use legislation that enables the transfer of a person with an intellectual disability from prison to hospital or another secure treatment

facility for a period of assessment. Such an assessment, whether community, hospital, or centre-based, provides the means whereby the factors surrounding a person's offending can be established so that the Court is well informed and an appropriate sentence passed. Forensic mental health involvement with a person with intellectual disability is of particular value when the offending took place in the context of a serious mental health problem, such as depression, and where there would appear to be a close relationship between the offending and mental ill-health. Treatment of the depression, for example, may be likely to reduce the probability of offending in the future. Treatments, such as anger management, and social measures to ensure appropriate support when living in the community, may also be important depending on the nature of that particular person's offence, the relationship of that offence to the nature of their disabilities, and the factors surrounding the offending. Specific treatment strategies have been developed, and can be delivered intensively, with benefits in reducing recidivism, to people with intellectual disabilities convicted of some more serious crimes, such as sexual offences and arson.

9.4 Implications for Policy and Practice

- **Services are required to support people with intellectual disabilities who may be suspected of, or are convicted of, a criminal offence. There is a need for legislation that ensures that this potentially vulnerable group of people has additional support and legal protection under such circumstances.**
- **Offending can be a form of mental or behavioural disorder with a potentially serious outcome for the person concerned, including deprivation of liberty. There should be a partnership between criminal justice agencies and health services to ensure that the factors that have contributed to the offending can be brought before the Court to inform sentencing.**
- **Additional mental health problems, drug and alcohol abuse, and social factors, such as homelessness and unemployment, may increase the risk of offending by a person with an intellectual disability and lead to further social exclusion. Preventive measures include meaningful employment opportunities, and housing, together with assessment and treatment services, and should be available to people with**

intellectual disabilities.

10.0 Ethical Considerations and Issues of Consent

10.1 The United Nations Declaration of Human Rights and associated Rules requires that people with intellectual disability are treated with respect, have the same rights as the rest of the population, and most importantly, the right to proper care and to freedom from degrading and inhumane treatment. People with intellectual disability are vulnerable to abuse and exploitation, to maltreatment in the criminal justice system, and to neglect generally within society. The same is also true for people in the population with severe and persistent mental disorders, or who abuse alcohol or drugs or are homeless. Thus, the combination of an intellectual disability, severe mental health problems and, sometimes, serious social disadvantage can be devastating. Countries differ in the nature of the legislation they have enacted related to disability issues and individual rights, but laws addressing issues of discrimination on the grounds of disability or enabling special support within the criminal justices system are particularly important to the protection of the human and civil rights of people with intellectual disabilities.

10.2 One specific and very important aspect of ethical concerns involves issues of consent and the capacity of people with an intellectual disability to consent to health and allied health treatments, to engage in management of financial affairs, and other matters of personal and social import. In the past, actions such as sterilisation without consent were justified on inappropriate grounds and would now be seen as discriminatory against people on the grounds of disability or mental ill-health, and obviously not in the best interests of the individuals concerned. It is therefore critically important that countries have an appropriate legal framework, in keeping with the UN Declaration of Human Rights or the European Charter of Human Rights, that enables healthcare and other decisions to be made for those who lack capacity, but protects them against exploitation, neglect, and abuse. For children, parents will have that responsibility to ensure individual rights, but for adults there may or may not be a clear framework that provides a just means of substitute decision-making when an adult with intellectual disability lacks the ability (i.e., capacity) to make important decisions independently. Countries vary as to whether case law (i.e., common law) or statute provide the legal framework for lawful action in this context (for example, guardianship, and mental health or mental incapacity legislation). However, some general principles apply with

respect to healthcare decisions: a) it is generally accepted that adults have the right to determine for themselves whether or not to accept health recommendations and to consent to participation in research or treatment; b) providing an adult has the capacity to consent, to contravene his or her wishes may be unlawful; c) if an adult lacks the capacity to consent (e.g., due to being unconscious, or because of severe dementia or intellectual disability) it should be possible to provide treatment, even though the person cannot consent, providing that the particular treatment is in the person's best interest (e.g., to save a life, prevent disability, reduce pain); and d) surrogate or substituted decision-making provisions under law can assist timely and appropriate provision of treatment services. The key, ethical principles are therefore respect for an adult autonomy, the central importance of decision-making capacity in determining whether personal autonomy may be overridden, and the concept of 'best interests' in determining a course of action when a person lacks capacity. Whilst what is in a person's 'best interest' may be generally agreed situations can arise whereby there are disagreements between different parties. A judicial forum for the resolution of such disagreements is required.

10.3 Decision-Making Capacity: It is generally accepted that decision-making capacity is decision specific. For example, a person with an intellectual disability may have the capacity to make decisions about some aspects of their lives, but not others. In the specific context of a decision having to be made, capacity includes the ability to comprehend the nature of the decision in question, appreciate the options and associated risks and benefits, and the ability to communicate a choice. Where, for example, treatment or admission to hospital is advised, an assessment of capacity (using the above concepts) is necessary to determine the extent to which the person is able to consent. If a person with an intellectual disability appears to lack capacity to make a specific treatment decision and is advised to undergo treatment which is clearly in his or her best interest, then family and other care staff have a responsibility to help the person become informed through the use of different methods of communication, books and pictures, videos, etc. Even if fully informed consent is not possible, maximally informed assent and attempting to determine and heed the wishes of the person concerned should be the goal.

10.4 Implications for Policy and Practice

- **Services for people with intellectual disabilities must conform to acceptable ethical**

standards and those working in services should have due respect for the freedoms and rights of people with intellectual disabilities that are established in international declarations and conventions to which their country is a signatory, as well as national legislation or policies affirming these freedoms and rights.

- **Professionals and other personnel serving and supporting people with intellectual disabilities should be knowledgeable about the legislative framework within which they work and to be able to balance an individual's right to respect for his or her autonomy with an appreciation of their need for care, protection, and at times, treatment.**

11.0 Research

11.1 The purpose of research is to inform and to enable the evaluation of specific hypotheses thereby leading to the advancement of knowledge and, in the case of health and allied healthcare, more informed and effective interventions. People with intellectual disabilities have the same right as others to expect that resources will be devoted to addressing health and social issues pertinent to them and that research will be undertaken that will lead to better health or health-related services more generally. However, there is also a history of unethical research and experimentation undertaken on people with intellectual disabilities who did not consent and were not in a position to refuse, involving, at one time or another, most westernised nations. There are widely recognised guidelines that help resolve this potential tension between the potential for exploitation, on the one hand, and ensuring that people with intellectual disabilities, like other people, benefit from research, on the other (e.g., World Health Organisation, 1993). These include: a) all research should be subject to the approval of an independent ethical committee; b) where possible, consent must be obtained and, at a minimum, fully informed assent (and there is evidence that this principle is being further strengthened in several nations); c) where the person is unable to consent the agreement of an appropriate other person must be obtained; d) the research should be the least invasive possible and carried out with no more than very minimal risks; e) the research should have discernible potential to benefit the research subjects and the nature of the research (e.g., efficacy of treatment of conditions occurring among people with intellectual disabilities) should require the participation of people with intellectual disabilities; and f) the involvement of people with intellectual disabilities in research, as in the case of any other research

subjects, should be free from coercion and subject to periodic or continuing independent review.

11.2 Whilst some of the factors that might contribute to mental ill-health are broadly understood, there is very limited understanding as to the mechanisms involved and the nature of particular protective factors. Research is required to identify relative contributions of biological, psychological, and social factors to mental ill-health and behaviour disorders, both generally and with respect to specific conditions. To do so, assessment tools need to be further refined and validated, and most importantly, collaborative research strategies must be developed that are not uniquely wedded to one theoretical model but can combine different intervention methodologies based on complementary models. Case controlled and prospective studies are required to determine the onset and course of mental ill-health as it affects people with intellectual disabilities, as well as determinants of risk, course, and treatment response. Biological, psychological, and behavioural research methods need to be brought to bear to investigate such issues as the mechanisms by which specific risks are associated with particular syndromes, for example, Alzheimer disease and Down syndrome, self-injury and Lesch-Nyhan syndrome, and severe over-eating and obsessions with Prader-Willi syndrome. Other questions related to how mental state abnormalities, patterns of development, and psychological and behavioural theories of learning inter-relate in explaining the character, onset, and responsiveness to treatment of mental and behaviour disorders among people with intellectual disabilities need addressing. Little is known about the influence upon the development of people with intellectual disabilities associated with differing ethnic and cultural attitudes and perceptions of intellectual disability, mental ill-health, and the combined presence of these conditions. Changing age structures in many countries are creating new challenges such as the diagnosis and treatment of dementia as it affects people with intellectual disability, and the impact of ageing more generally on mental health and cognitive functioning in this population.

11.3 Implications for Policy and Practice

- **Conduct of research that informs the treatment and management of mental ill-health and behaviour disorders affecting people with intellectual disabilities should have a high priority, but must be undertaken within a transparent and ethical context.**

- **The major priorities for research are to establish the research methodologies and assessment techniques that will enable investigation of factors that increase or decrease risk of mental ill-health and behaviour disorders and thereby lead to new and effective preventative and intervention strategies.**

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