Caring for children and adolescents with mental disorders

Setting WHO directions

World Health Organization
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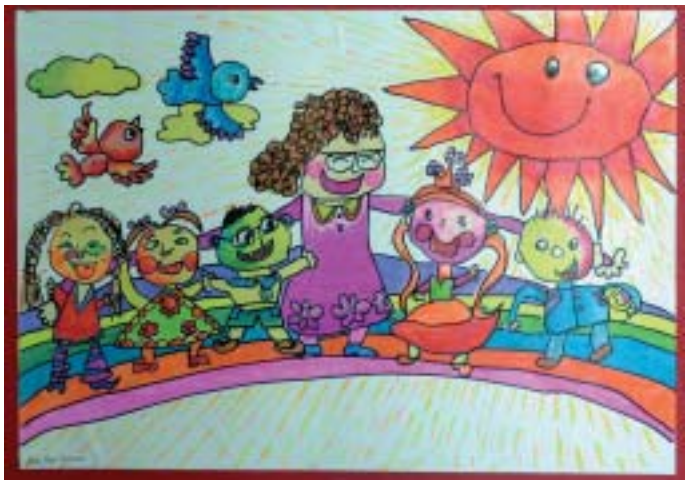
Foreword



Throughout the history of the WHO Mental Health Programme the attention dedicated to children and adolescents has not been commensurate with that dedicated to adults and the elderly. Yet, from both demographic and epidemiological perspectives – as well as from the burden of disease – mental disorders of children and adolescents represent a key area of concern.

Accordingly, WHO convened a meeting of leading world experts and organizations in the area of child and adolescent psychiatry – to whom our gratitude is extended – to review contemporary issues and suggest concrete action in this area. Their contribution was later expanded through additional information, from a variety of sources.

We are well aware of the risks inherent of medicalization in any discussion of mental health problems of children and adolescents – or worse, its "psychiatrization" – of problems of normal living and normal psychosocial development. We also aware of the many spurious interests endangering an unbiased, objective approach to normal developmental issues, that tend to unduly put many problems of normal living in the basket of "medical or mental disorders".

However, this does not justify a responsible public health officer from shunning action that provides adequate and appropriate interventions for children and adolescents with unequivocal mental disorders.

Therefore, this document has a two-fold purpose: on the one hand, it aspires to provide an updated perspective on this topic with technical clarity and, on the other hand, is issued as a contribution to raise awareness of pertinent issues among professionals and policy makers.

Dr Benedetto Saraceno
Director, Department of Mental Health and Substance Dependence

Introduction

The lack of attention to the mental health of children and adolescents may lead to mental disorders with lifelong consequences, undermines compliance with health regimens, and reduces the capacity of societies to be safe and productive. Contemporary recognition of child and adolescent mental disorders and advances in the care of children and adolescents with mental disorders provide an incentive to synthesize current knowledge, identify issues for future exploration, and consider appropriate policies.

Areas of primary concern are:

- Magnitude of the burden of child and adolescent mental disorders
- Advances made in treatment and diagnosis
- Barriers to treatment
- Trends in care for children and adolescents with mental disorders

In this respect, the World Health Organization has developed a series of activities designed to identify treatment gap, promote training, encourage rational treatment, and promulgate model policy.

One of these activities was a meeting on "Caring for Children and Adolescents with Mental Disorders: Setting WHO Directions" sponsored by the Department of Mental Health and Substance Dependence, held in January 31 and February 1, 2002. The meeting brought together leaders in the care of children and adolescents with mental disorders from around the world. The focus of the meeting was on the care of children and adolescents with mental disorders with special emphasis on emerging issues impacting developing countries.

This Report presents updated information useful for the formulation of a Child and Adolescent Mental Health Care Plan, based on findings which emerged during the above-mentioned meeting, as well as from other sources.

Child and adolescent mental health is an essential part of overall health

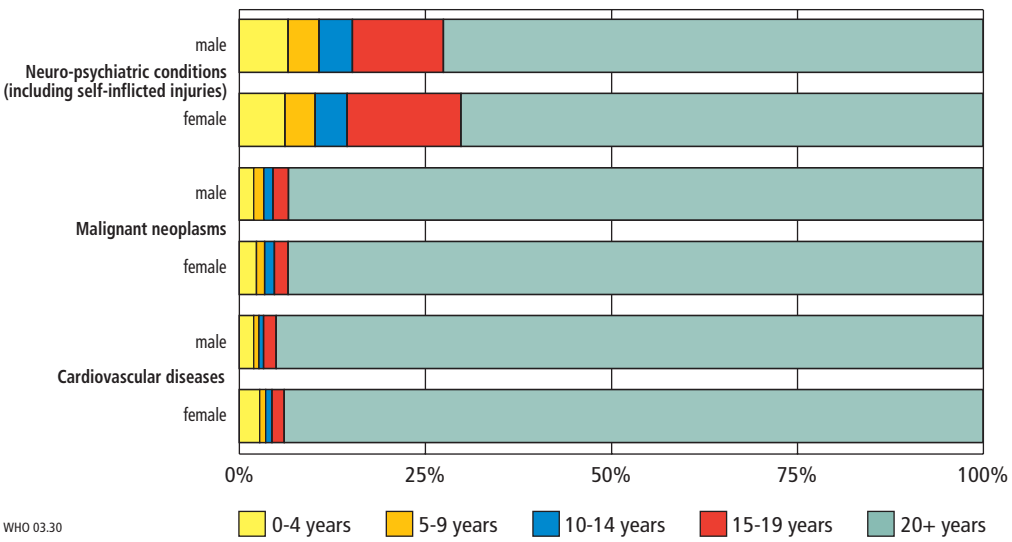
Burden of Disease

The magnitude of the burden of disease related to child and adolescent mental disorders is understood by clinicians and parents, but has until recently been difficult to quantify. Now, with world-wide crises involving children impacted by war, exploited for labor and sex, orphaned by AIDS, and forced to migrate for economic and political reasons the dimensions of the burden of compromised mental health and mental disorders are increasingly evident and quantifiable. It is estimated that in 26 African countries the number of children orphaned for any reason will more than double by 2010 and 68% of these will be as a result of AIDS. 40 million children in 23 developing countries will lose one or both parents by 2010 (Foster, 2002).

Absence from education, underachievement leading to dependency, involvement in criminal activity, the use of illicit drugs, the inability to benefit from rehabilitation, comorbid medical conditions are but some of the very many impacts that have an associated cost.

To understand child and adolescent mental health needs it is first necessary to understand the overall dimensions of what are called non-communicable diseases affecting children, the impact of the infectious diseases with direct and indirect impact on the mental health of children, and lastly the available data on diagnosable psychopathology (Figures 1 and 2). The DALY calculation underrepresents disability caused by mental

Figure 1. **World: DALYs in 2000 attributable to selected causes, by age and sex**



disorders in children and adolescents because childhood psychiatric disorders such as ADHD, conduct disorder, learning disorder, mood disorders, pervasive developmental disorders and mental retardation, among others, were not included (Fayyad, 2001).

It is important to highlight the following:

- World-wide up to 20% of children and adolescents suffer from a disabling mental illness (WHR, 2000).
- World-wide suicide is the 3rd leading cause of death among adolescents (WHR 2001).
- Major depressive disorder (MDD) often has an onset in adolescence, across diverse countries, and is associated with substantial psychosocial impairment and risk of suicide (Weissman, 1999)

Conduct disorder related behaviors tend to persist into adolescence and adult life through drug abuse, juvenile delinquency, adult crime, antisocial behavior, marital problems, poor employee relations, unemployment, interpersonal problems, and poor physical health (Patterson, DeBaryshe, & Ramsey, 1989). Scott (2002) demonstrated increased costs for care and to society in later years from the childhood diagnosis of conduct disorder. Leibson (2001) showed that over a nine year period the median medical costs for children with ADHD were $4,306.00 compared with $1,944.00 for children without ADHD. The costs are due to higher rates of admission to hospital emergency and outpatient departments and visits to primary care physicians. The study excluded the costs of treatment by psychiatrists and mental health professionals.

Weissman et al. (1999) demonstrated in a longitudinal study the poor outcome of adolescent onset major depressive disorder. There was continuity and specificity related to the adolescent onset which continued into adulthood and was associated with high rates of suicide and suicide attempts, increased rates of psychiatric and medical hospitalizations, psychosocial impairment and lower educational achievement. Geller (2001) reported that children with pre-purbertal major depressive disorder, as adults, had significantly higher rates than a normal comparison group of bi-polar disorder, major depressive disorder, substance use disorders and suicidality.

Eating disorders are becoming more prevalent and observable across cultures (Becker, 2002) These difficult to treat disorders also demonstrate a continuity between adolescent onset and adult risk for the presence of an eating disorder (Kotler, 2001). 21.6% of college age females with eating disorders also met clinical criteria 10 years later (Heatherton, 1997).

After taking account of confounding factors Woodward and Fergusson (2001) found that significant associations remained between the number of anxiety disorders reported in adolescence and young people's later risks of anxiety disorder, major depression, illicit drug dependence, and failure to attend university.

Understanding Child and Adolescent Mental Disorders

Priority disorders

Child and adolescent mental disorders can be considered from a number of perspectives. The following disorders are identified as priority areas based on their higher frequency of occurrence, degree of associated impairment, therapeutic possibilities (particularly at primary health care level -PHC) and long-term care consequences.[1]

Early childhood

- **Learning disorders.** High incidence and prevalence, with serious implications for future productivity. Treatment is limited and school focused; obtaining occupational self-sufficiency is the goal. They may be associated with hyperkinetic disorders.
- **Hyperkinetic disorders (ADHD).** Presumed high incidence, greatly influenced by media and pharmaceutical awareness campaigns. Highly treatable at relatively low cost when the diagnosis is appropriately made. Long-term consequences relate to reports of poorer occupational attainment, and increased co-morbid psychiatric illness and substance use disorders.

Middle childhood

- **Tics (Tourette's syndrome).** More recently diagnosed with an incidence and prevalence not previously appreciated. The disorder now appears to be treatable without highly specialized interventions. Untreated, this disorder has high degree of stigmatization, and social isolation.

Adolescence

- **Depression and associated suicide.** Depression is now recognized as a diagnosable disorder in children and adolescents. This in itself is an advance. Refining the diagnosis and recognizing its broad impact is ongoing. The magnitude of the association of depression and aggression with suicide remains open to confirmation on a general population basis but are, nevertheless important clinical issues. It is clear that the combination of depression with substance abuse puts children and adolescents at greater risk for suicide.

1 Nomenclature and diagnostic guidelines for these disorders are found in ICD-10 (WHO, 1992).

- **Psychosis**. The early identification of psychotic conditions is important for they are not always as obvious as would be thought. Psychoses can result in a host of maladaptive behaviors. The early treatment of psychotic disorders such as schizophrenia not only brings relief to patients, families and society, but improves the prognosis. Toxic psychoses are treatable when recognized with a dramatic reduction in symptoms and often rapid return to functioning.

It should be noted that *medical disorders often associated with psychiatric symptoms*, such as diabetes and seizure disorders, might be co-occurring with all the disorders noted above. Substance use disorders are also significant co-morbid conditions that can alter the course of illness, treatment and outcome, and represent a growing in importance issue in the treatment of children and adolescents. Co-morbid substance use disorders or substance abuse can add dramatically to the degree of morbidity and functional incapacity of the individual, and may influence the type of care provided.

In addition to the above noted disorders categorized by age, which could be appropriately managed at the PHC level, the following disorders should be considered for treatment at higher levels of complexity:

- **Pervasive Development Disorder**. Low incidence with high morbidity and need for intensive rehabilitative efforts involving many sectors including education, rehabilitation and social services. Poor occupational attainment has a great cost to families and societies dependent on cultural setting and community acceptance. Milder cases may first present as learning delays and less with problems in socialization.

- **Attachment disorders.** They appear in infancy and have a major long-term impact, but appear to be modifiable with increasingly common early intervention programs. This area of concern focuses attention on the need for programs with a maternal-infant focus.

- **Anxiety disorders**. A heterogeneous category of disorders with variable diagnosis in even the most sophisticated settings. Interventions are many with varying results. At the extreme phobias and panic disorder can lead to significant social isolation and lack of occupational attainment. When school refusal is included in this diagnostic grouping then the consequences can be seen as having multi-sectorial implications for both diagnosis and treatment.

- **Conduct disorder/anti-social personality**. The manifestations of conduct disorder may vary across cultures. This diagnosis is most commonly made when associated with anti-social or defiant behavior, but it can have other manifestations. It should not be made prematurely because once made it is often seen as having such a negative prognosis that it may establish a self-fulfilling prophecy. Treatments are multi-sectorial with quite variable outcomes and require a comprehensive plan for there to be any hope of success

• **Substance abuse**. While it is often impossible to diagnose children as meeting the criteria for substance dependence, whether it be alcohol or other drugs, the serious manifestations of the abuse of substances is evident. Further, the use of drugs and alco-

hol clearly alters the diagnosis and treatment of all other disorders that may be co-morbid.

- **Eating disorders**. These disorders are now seen in developing as well as developed countries and may even manifest themselves in the face of apparent starvation. It is believed that a contributant in the rise of eating disorders is the exposure to Western media and its influence on desirable body characteristics.

Epilepsy

Special attention has to be given to epilepsy. It has clearly different patterns of diagnosis and treatment in different countries. The use of child neurologists or other specialty providers is more common for diagnosis and treatment than thought.

However, ongoing care remains largely in the primary care sector. Despite widespread information campaigns about epilepsy many seizure disorders in children and adolescents go unrecognized and are only discovered on referral to a psychiatrist. There is clearly a need for enhanced training to recognize the relationship between seizure disorders and the signs and symptoms of other mental disorders.

The WHO Global Campaign on Epilepsy has identified the major treatment gap that exists in this most treatable of disorders.

Source: WHO

Context for the diagnosis of mental disorders

In considering the care for children and adolescents with mental disorders the importance of the ***contextual understanding and context*** of the disorders must be stressed. This contextual understanding places a special importance on understanding the environment of the child and the adolescent, that is, family, community and nation. Also, specific situations might impact on diagnosing a mental disorder in children and adolescents, such as: exposure to conflict, economic and psychosocial adversity, voluntary and forced migration, effects of AIDS/HIV and the perception of the "rights" of the child and adolescent in a given society.

Disorders of mental functioning cannot be seen as static diagnostic labels, but rather must be seen as dynamic responses to social/environmental stressors. This does not imply that those disorders now known to have a biological, presumed genetic component, are to be negated. Rather, the weight is given to appreciating the potentially unique impact of environmental factors in the expression of these and other disorders.

Cultural relevance and the appropriateness of diagnosis

The *diagnosis of children and adolescents cannot be considered solely from a Western perspective*. While it is recognized that, in general, the same disorders exist throughout the world as supported by the available literature, it is equally clear that presentations may vary. This variability in presentation and the linkage to diagnostic nomenclatures is an area requiring further study.

A very real concern is the applicability of the refined diagnostic categories used in the West by trained clinicians in areas where there are limited resources. One should look at *broader categories of disorder* rather than *narrower disease definitions*. The use of broader categories of diagnosis is more readily understood by professionals and non-professionals without prior mental health training. With a sense that one could grasp a diagnosis, health workers would be more likely to make diagnoses and treat or refer for treatment with a greater understanding.

For those in developing countries or countries in transition, a major concern is to address the problem of children in *"difficult circumstances"* such as conflict, displacement, hunger, etc. Using the terminology *"difficult circumstances"* reflects what might otherwise be considered reactive disorders. The ability to differentiate these reactive disorders from those leading to possibly longer term impairment has implications for care and resource utilization.

It is of particular importance in developing countries to emphasize the degree of *impairment/disability* associated with a diagnosis. The degree of disability varies with the circumstances of the child, the nature of the community, the demands of the society, the family, etc. Ultimately, the specific diagnosis may be less important than the degree of impairment and the ability of the individual to participate in society.

Treatment of priority disorders

Although there is still a debate over the appropriateness of using medication in the treatment of children and adolescents with mental disorders, the benefit of the rational use of this approach cannot be denied in the case of some specific mental disorders. It must be stressed that the vast majority of psychopharmacological treatments remain "off label" or without official sanction for use in children. The use is governed by the regulations of individual countries and international sanctioning bodies. This acquires special relevance when considering the transfer of technology to and training of PHC personnel. Psychotherapeutic and psychosocial interventions for children and adolescents with mental disorders and for their families remain a relatively sophisticated field more appropriate for specialized care (ie. secondary and tertiary levels) than to PHC. An exception to this are counselling and special interventions with school staff which can be integrated into PHC.

Table 1. summarizes the intervention possibilities for priority mental disorders seen in children and adolescents.

Table 1. Therapeutic interventions for priority mental disorders of children and adolescents

Treatment / Disorder	Psycho-therapy	Cognitive-behavioral therapy	Psycho-pharmaco-therapy	Family therapy	School intervention	Counselling	Specialized interventions	Other
Learning disorders			■		■	■		■
Hyperkinetic/ADHD		■	*		■			
Tics		■	■	■				
Depression (and suicidal behaviors)	■	■	*	■				
Psychoses			■	■	■		■	
Schizophrenia			■	■				

*Specific treatment depends on the age of the child or adolescent.

Barriers to Care

In spite of the existence of effective interventions for the care of children and adolescents with mental disorders, a huge proportion of those with these disorders do not have access to care due to a series of barriers. These barriers to treatment are several, but reflect a few dominant themes:

- Lack of resources (financial, human resources, facilities)
- Stigma
- Other barriers

Barriers to care are evident in both the developed and developing world. Though progress has been made in developing effective treatments, children and adolescents with mental disorders and their caregivers remain stigmatized. Economic decline in developed countries and competition for financial resources in developing countries almost universally impacts mental health services disproportionately. Priority is given to those illnesses labelled as physical without the recognition of the association with mental disorders or recognition of the burden associated with mental disorders.

For child and adolescent mental disorders, which are known to progress and sometimes worsen into adulthood, the impact of inattention to treatment for later morbidity and mortality is demonstrable. In this regard, some argue that it is crucial to link overall health with concerns for mental health.

Improving mental health leads to:

- improved physical health
- enhanced productivity
- increased stability

On the other hand, failure to improve mental health leads to:

- increased crime
- unemployment
- violence
- other risk related behaviors

Lack of Resources (including financial, trained personnel and facilities)

Lack of resources for child and adolescent mental health treatment services is a universal problem. In developed countries there are problems of maldistribution, a declining enrollment in child psychiatry training programs, and a recent reduction in those working in community settings. In the developing world there is an almost universal lack of enough trained individuals to staff even basic child and adolescent mental health treatment facilities and certainly not enough to implement a full continuum of care as conventionally defined.

Creative training programs for a broad range of previously trained pediatricians and adult psychiatrists can add to the pool of child mental health trained individuals at one end of the spectrum, but there is also the need to train larger numbers of primary care workers, religious personnel, school personnel, and community workers in basic child mental health diagnosis and treatment methods. Some have stated that new models of training in the primary care sector are needed to enhance attention to child and adolescent mental disorders since primary care workers working with children are already so overwhelmed. The area of training to support peer counselling is of importance, especially as it may impact peer risk behaviors. Specialized training in the diagnosis and treatment of child and adolescent mental disorders for non-specialist nurses has been demonstrated to have a major impact in developing countries.

In developed countries treatment for child and adolescent mental disorders is historically under-funded. In developing countries financing schemes are being adopted without recognition of their impact on existing systems that currently provide care. The disruptive effect is great and there are no new financial resources being allocated in the schemes to provide for the development of new systems of care that would be an enhancement over past services. In some instances, access to care is demonstrably worse in the new schemes due to disruption of existing primary health care systems.

The work of NGOs is evident in many areas of the developing world and in trauma affected regions. NGOs often focus on specialized areas of interest, such as, child abuse, but it should be recognized that these NGO initiatives need to consider sustainability and work to enhance the overall mental health treatment capacity in the areas where they work. When conceived of as part of a long-term, integrated plan of care for children and adolescents NGO sponsored programs, even if quite targeted can provide an overall enhancement of a community's mental health resources.

Stigma (at the local, national and international level)

It is now well documented that stigma associated with those who are mentally ill, and ironically with those providing for the treatment of those with mental disorders, is evident at all levels of society.

There is a need to support ongoing campaigns to reduce stigma not just as a social exercise, but directly as it relates to access to care and the support of building a continuum of care.

A Model Anti-Stigma Campaign

The WHO School Contest, held as part of World Health Day 2001 which had the theme "Stop Exclusion: Dare to Care," is a model of an anti-stigma campaign that involved all strata of society, had political impact, and yielded effective products that focused attention on the problem of stigma.

Through Children's Eyes, a collection of drawings and stories presenting the viewpoint of youth on mental disorders is a product from World Health Day. The book provides brief descriptions of most common mental disorders in children and adolescents and has a teacher guide to facilitate classroom discussion of mental disorders and stigma.

Source: WHO

Other Barriers that Deny or Delay Services

Lack of transportation

While the needs of urban populations are obvious and deserving of focused attention, the plight of rural populations cannot be ignored. In fact, being able to diagnose and treat individuals in their local communities is not only appropriate, but will lessen the burden on urban centers and reduce the potential for urban "drift" of those marginalized in their communities.

A Mobile Child Mental Health Service in Germany:

A mobile service in Marburg, Germany uses a team of three professionals (child psychiatrist, psychologist and social worker) who go through different towns and villages by car and hold consultation hours devoted to three tasks:

1. Follow-up of patients who had been previously hospitalized;
2. New child psychiatric consultations on site; and
3. Supervision of institutions for children.

Similar services have been developed in Thailand.

Source: Prof Remschmidt

Lack of ability to communicate effectively in the patient's native language

Care for the mentally ill is language dependent. A mental disorder can rarely be adequately diagnosed or treated without verbal communication. Understanding the idiom of a local language and specialized meanings is important in working with patients. With child and adolescent focused clinicians a significant part of their training involves learning how to relate to their patients through the appropriate use of language and non-verbal interactive skills. Thus, to the extent possible, it is always preferable to have workers available who can communicate with full knowledge of the patient's language and culture.

Lack of public knowledge about mental disorders in children and adolescents

Historically, recognition that children and adolescents have a mental life is of recent origin. Children previously were not recognized as having feelings, including depression or other mental disorders, such as, ADHD/Hyperactivity Disorder. Now, this knowledge is available. Enhanced efforts are needed to get objective information into the hands of parents and providers. It is now too often the case that information about mental disorders is conveyed by industry. While this education may be very beneficial in sensitizing populations to the mental health needs of children and adolescents it also holds the risk of distorted messages being conveyed to an anxious and needy populous, may limit the full potential of an appropriate diagnostic evaluation and limit the treatment options considered.

Interventions to Reduce the Barriers to Care

Improving family communication

Improving the ability of families to address potentially debilitating mental disorders in the context of the family is a key to humane care. Improving communication about emotions and involving the child in the family in meaningful ways can reduce the consequences of isolation that lead to adverse outcomes

Increasing awareness of psychosocial development

In the family, schools, religious organizations and throughout communities, increasing knowledge about psychosocial development in the most basic terms can reduce barriers to care, increase the inclusion of young people and otherwise reduce the noxious contexts that can perpetuate disorders. For instance, understanding that adolescents can be moody, that a concern with socialization is normal, that young people strive to be autonomous can reduce conflicts in the family, enhance the child or adolescents sense of well-being and reduce the negative effects of conflict that can lead to psychopathology associated with poor adjustment.

Educating religious personnel about mental disorders in effort to establish a treatment alliance and appropriate referral

A key resource for child and adolescent mental health care in communities are traditional and more formal religious entities. In rural and urban areas throughout the world religious leaders and institutions now shelter and otherwise support individuals with diagnosable mental disorders. The understanding of the condition of the individuals being cared for varies widely and the interventions are of equally diverse nature. There is an opportunity to educate these informal providers about mental disorders and to engage them in an alliance to provide appropriate care.

Encourage the development of national child and adolescent mental health policy

While it can be debated as to the appropriateness of establishing independent child and adolescent mental health policy, it is clear that to identify a focus on care for children and adolescents with mental disorders within general mental health policy, health policy, educational policy, social welfare policy will provide a framework for program and resource development.

Urban mode mental health work: HangZhou, China

In Hangzhou City, with the rapid development of the economy, the mental health of the citizens is becoming a more prominent public health concern. Since 1998, the Hangzhou Municipal Government put mental health related activities on the official agenda. The Hangzhou "mental health work office" was set up to plan and manage mental health work in the whole city. Meanwhile, the municipal financial department appropriated special funds. Through a three-year plan, Hangzhou has reformed the structure of urban mental health services in two ways.

Vertically, Hangzhou has established institutes for mental health work at three organizational levels: city, county (district) and town (street). A series of institutes, offices and health departments undertake the management and coordination of mental health work (plans, program monitoring, and collect data) within an administrative area.

Horizontally, the Public Health Bureau of Hangzhou established *mental health centers* at appointed hospitals, and institutes for mental health consultation or mental health services; the Educational Committee established a *mental health tutoring center for students*, and schools at all levels established mental health tutoring and consulting institutes for students. *Infants' mental health tutoring centers* were established in the kindergartens; the Youth League organized youth to carry out mental health training related to self-protection; and *mental service stations* were established to provide mental health services for officials, soldiers, and criminals in prison. All mental health services promote knowledge dissemination.

Source: Dr. Linyan Su

Utilizing scarce resources

In developing countries or areas of acute conflict the role played by NGOs can be vital. There is a perceived need to reduce competition among NGOs, improve co-ordination and require a plan to sustain the work after crises. In essence, there should be the obligation to build a system of care and leave something that builds in-country capacity.

Providers and consumers need to be trained for policy and advocacy in countries where systems of care are evolving. Advocacy and policy training is needed to make effective arguments for child and adolescent mental health services. A comprehensive, sophisticated paper on the economic impact of not providing services to children and adolescents and the cost/benefit of providing services is needed. This is a place where WHO can have an effective role along with the development of model policy and services guidance.

An NGO for children with hyperkinetic disorders in Lebanon:

Local child mental health professionals helped parents of ADHD children come together for the formation of an NGO – the Lebanese ADHD Association.

In collaboration with child and adolescent psychiatrists and psychologists, this association has been raising public awareness about ADHD in schools and amongst NGOs that care for children, as well as advocating for the rights of children and adolescents with ADHD to have their special educational need recognized in schools as well as on a national governmental level.

Source: Dr. John Fayyad

Service Organization and Policy

The current world-wide situation in both developing and developing countries as far as policy for caring for children and adolescents with mental disorders reflects a virtual absence of specific policies. Recognition of the importance of policy, the difficulty in promulgating policy and the compromises that might be needed in policy development in low resource countries is essential.

The development of child and adolescent mental health services in the absence of specific national policy leads to: (1) fragmentation of services, (2) inefficient utilization of scarce resources, (3) inability to provide effective advocacy for priority concerns, (4) lack of constituent participation in program development and (5) an inability to incorporate new knowledge in a systematic fashion.

Experience indicates that, at the least, policy should set out broad principles based on current knowledge, and that one form of policy or services guidance is not appropriate for all countries. Therefore, it is suggested that *policy and services guidance should follow the matrix model adopted in the WHO World Health Report 2001 which articulates a set of appropriate services depending on the economic/resource status of a nation. The WHO is promulgating model policy for the implementation of child and adolescent mental health services*. Experience indicates that the integration of a child and adolescent mental health component into primary health care is an essential part of any approach, at least in developing countries.

Legislation

Closely related to the need for policy is that for legislation that may influence the implementation of policy or focus on categorical issues with mental health relevance. It is not so much an absence of laws pertaining to children and adolescents receiving appropriate clinical care, such as, the opposition to incarceration or abuse, but rather a weakness in the enforcement of existing laws. A prime example of this gap in enforcement is seen with the large number of elegant laws relating to child abuse that are not enforced. The same is true for the provision of the appropriate care of children and adolescents with mental retardation, since it is noted that the treatment of the mentally retarded continues to lag even that of people with other forms of mental disorders.

Increasing awareness about the support for appropriate care for mental disorders engendered in the UN Convention on the Rights of the Child is key to program and policy development in many countries. The Convention can also be used to support the modification of existing systems and for improving access to appropriate care. The UN Convention supports the important role of the child in the family context and of access to education, rehabilitation and a wholesome community life.

Promoting the human rights of children in Costa Rica:

Fundación Paniamor

Mission: To oversee and assure the verification of children's human rights (to prevent the violation of children's human rights).

Strategy: Only preventive interventions: surface campaigns, information, education, training, skills development, lobbying, etc.

Outcomes:

1. Increase awareness and prevention of child maltreatment,
2. Promote and participate in the creation or development of new legislation to improve the situation of children and to protect their human rights,
3. Reintegration of high risk adolescents to school and/or train them to be employable,
4. Creation of the largest database in Central America on child welfare.

Funding: Private, national and international, International organizations.

Source: Luis Diego Herrera Amighetti, President of Paniamor

Primary health care, community care and schools

Primary health care workers, including physicians, have a very limited understanding of current concepts of diagnosis and treatment of mental disorders in children and adolescents. This hinders the ability to provide services to children and adolescents and may add to the stigma of mental disorders in these young people. Hence, it is a priority to get current knowledge in a usable form disseminated to practitioners and policy makers.

The pressures on pediatric practitioners are very great resulting in the concern that discussing child mental disorders will so broaden the physician or caregivers involvement with the family that they will be further overwhelmed. Therefore, they tend to not ask key mental health questions. Pediatricians and other primary care workers must be given an increased literacy about child mental disorders in their training to reduce misconceptions about the effectiveness and feasibility of care.

As services are evolving, a distinction needs to be made between primary care and community care. The latter refers to the utilization of parents, NGOs and other resources available in the community (e.g. schools) to provide services in a coordinated fashion. This is an alternative to attempting to build on the already burdened primary care provider system that may be in existence. This model is potentially more flexible and can be implemented more easily in resource poor areas. It clearly calls for a multi-sectorial, not just a multi-disciplinary, approach that helps in decreasing barriers between those working with similar populations of children; these barriers arise due to the isolation for child treatment domains even when one discipline trains another.

In this respect, the importance of schools in the provision of mental health related services for children and adolescents is crucial. In some settings schools can be a primary venue for the delivery of diagnostic and treatment services, and in others the school can serve as a support for getting primary treatment elsewhere. Schools in all cases are to be viewed as a potential resource for the recognition of children and adolescents in need of formal diagnosis and treatment.

Continuum of care, guidelines and practice parameters

The concept of a continuum of care comes as the result of an awareness that fragmented services for children and adolescent lead to: (1) poor quality of care, (2) lack of compliance, and (3) an inability to maintain children and adolescents in least restrictive environments.

Developing a continuum of care requires an investment of financial resources and the training of professionals to utilize the spectrum of services included in a continuum. In developing countries the concept can be applied even though all the elements may not be currently present. The concept establishes a goal and can help to establish benchmarks for progress. Good epidemiological data helps to determine the precise balance of services needed in any continuum.

Modern trends in developing a continuum of care incorporate practice guidelines or practice parameters. The guidelines and practice parameters, derived from consensus panels of clinicians, provide roadmaps for how to approach the care of patients presenting with various symptoms and sets out methods of care including indications for the use of psychotropic medication, hospitalization, etc. These guidelines or practice parameters have been developed by professional organizations and consensus panels. *Lacking in most guidelines and practice parameters is a sensitivity to cultural issues*. Adopting such guidelines in developing countries should involve a review to establish cultural appropriateness.

Current Trends in Caring for Children and Adolescents with Mental Disorders

Developments in relation to the care of children and adolescents with mental disorders can be observed in many places. Strategies evolved and implemented in developed countries are often attempted in developing countries with quite variable results. Effective strategies in developing countries are slow to be recognized in developing countries. Among these are:

- Privatization
- Managed Care
- Direct marketing of psychotropic medication
- Parent, NGO, community involvement in mental health advocacy
- Respite Care

Privatization

There is an almost universal trend toward privatization of mental health services, even in countries with marginal economies. Privatization is seen as cost-saving and consistent with modern care as viewed in the West. The notion that privatization can take place without governmental oversight, strategic investment, or national policy has too often resulted in the dissolution of workable public systems, and the evolution of systems that exclude the most needy. These consequences of privatization can be seen in developing and developed countries.

The development of systems of care with a combination of public and private sector funding, with the option for choice depending on income level or need, and the provision of adequate incentives to maintain a balance of professional staffing in both systems is a goal that must be strived for in all societies.

For children and adolescents, the importance of schools in the provision of mental health services is crucial. In some settings schools can be a primary setting for diagnosis and treatment and in others the school can serve as a support for those getting their

primary treatment elsewhere. Schools in all cases are to be viewed as a potential resource for the recognition of children and adolescents in need of formal diagnosis and treatment.

As part of movements toward privatization in developing countries insurance schemes are being put in place along with managed care. The introduction of insurance as a way to control costs and reduce government expenditures is difficult at best in societies accustomed to health care as an entitlement. The adoption of insurance schemes developed in the West need careful scrutiny for applicability in developing countries which have few resources and the potential to see great inequalities in care emerge. The absence of an infra-structure to support a well managed and financed insurance program can lead to significant disruptions, the flight of professionals and the inadvertent denial of care to some of the most needy. *An exception to the negative view is the report from South Korea that in implementing a new mental health plan they have realized a 30% supplement for child mental health care!*

A "shared governance" example from United States of America:

The MHSPY is a program that has supported a "shared governance" model for addressing the mental health needs of adolescents and children. Five public and two private agencies are coordinated to focus on a group of "at risk" and ill children. Blended funding is used. By "blended" funding it is meant that each agency provides a portion of the money for the program. Family spokespersons and agency decision makers sit on the MHSPY Steering Committee. Health as well as mental health concerns are addressed by this governance model. Eligibility criteria for the youth and families to be served was established by consensus using readily available scales for impairment (CAFAS). The broad age range of 3 to 18 is accommodated, and priority is given to those with the greatest risk of "out of home" placement. Benefits include a long list of currently available services, seen as "usual care" plus a list of other programs developed in response to observed needs.

Every family gets a Care Manager who works to set up a Care Planning Team made up of professionals, non-professionals and natural resources. The Team creates a "mission" for the child. A strength-based assessment is done, needs identified and interventions planned. The Care Manager delivers some care, maintains a link to primary care and monitors all care. The Care Manager has a close relationship with the family, but is not a therapist. The outcome measure of "days out of home" dropped profoundly with this intervention. School, family and community measures improved. Service utilization shifted to less costly and restrictive services. Satisfaction and program retention is high.

Source: Dr. Katherine Grimes

Managed care

Managed care refers to the oversight of the provision of healthcare including mental health care by outside parties to control costs and quality. The emphasis appears often to be on reducing cost and secondarily on providing a more uniform quality of care. The impetus for managed care came from the observation of excessive costs in the provision of mental health services in the US in the 1980s and 90s when there were inappropriate

hospitalizations and other extraordinary expenses. It is clear that managed care for developing countries, if not focused on the provision of quality services, will impose an unnecessary addition to the cost of care rather than reducing inappropriate or excessive expenditures.

Adapting to socioeconomic transition in Bulgaria:

During the so called transitional period in Bulgaria it was difficult to transfer new knowledge and experience from child mental health and child psychiatry into stable structures. The following steps represent the most success:

1. The establishment of a model-type institution for child mental health (CAP clinic "St.Nicolas") with the Medical University of Sofia. Funded by outside NGO and with consultant help a model facility and program were developed.

2. Creation of an organizational model adapted to local cultural and health backgrounds with stability guaranteed. During 1997-2000 the following was seen:
- Evidence based medicine
- Evaluation of activities
- Separation of the diagnostic and therapeutic phases of work
- Mandated participation of the family
- Work with communities
- Creation of reciprocal bonds between child psychiatrists, schools and general practitioners.

3. Multiplication of the new model outside Sofia during the period 2001-2002.

An organizational workshop including representatives of the government, financial authorities, local authorities and visiting from consultants facilitated the process. In addition, there has been:
- Continuous education programs related to the new model;
- Cooperation with media;
- Encouragement by the professional association of child psychiatrists and allied professionals for the development of regional health teams
- Advocacy for the development of new financial and local authority support for new specialized facilities.

Another modern institution was created distant from Sofia. This was done despite financial difficulties in Bulgaria. The advocacy for better standards has been hastened with the new model.

Source: Prof. Nadia Polnareva

Direct marketing of medication

There is a great need for ethical guidelines to address the appropriate use and potential abuse of psychopharmacological medications with children. In the developing, as well as the developed world, there is an increasing reliance on pharmaceutical companies for education about mental disorders. In this scenario the potential exists to short circuit appropriate diagnostic evaluation and to generate unwarranted concerns about certain disorders based on a naïve understanding of symptoms. It is recognized that there are limited indications for the use of

psychotropic medications in children and adolescents, and that most current use is "off-label", though there is an encouraging trend toward supporting child and adolescent specific treatment research designed to ascertain the appropriateness and effectiveness of psychopharmacological treatments in children and adolescents. Medication/diagnosis specific approvals are now coming forth.

Respite Care

In developing and developed countries there is a great reliance on parents to provide care for their mentally ill child. This is often a time consuming and emotionally draining experience. It must be considered in developing systems of care that provisions be made for "respite care" to allow parental/family providers to continue to work outside the home, engage in the normal range of family activities, provide for the appropriate care of other family members and regain their energy.

A "Place of Healing" in South Africa:

The Empilweni ("Place of Healing") project was established in 1994 in Khayelitsha, an informal settlement area in Cape Town, South Africa, by the Department of Psychiatry of the University of Cape Town. Khayelitsha serves a population of over 500,000 people. The project arose following an epidemiological study in 1993 in which 64% of the children (age 6-16 years) were recorded as having at least one psychosocial problem. Funding for the project was provided mainly by the Department for International Development (UK).

The primary health care clinics in the area are too overloaded to deal effectively with child psychosocial problems, so an initiative was conceived to empower the community to manage the problems with training and support from mental health professionals at the University of Cape Town. Essentially, the project is a walk-in community mental health service staffed by community workers, local lay persons who are experientially trained using real cases. The workers perform case management, individual, group, parent and family counselling. Supervision is provided by a clinical psychologist on a weekly basis, and a qualified social worker is based at the centre. A child psychiatrist visits the center fortnightly for consultations, and cases may also be referred for other investigations and interventions. However, the majority of the problems are treated by the community workers themselves. Parents and community-based professionals are educated about child mental health problems by means of home, school and agency visits, workshops, and dissemination of information by hand or on community radio.

The most common problems managed at the project are: sexual abuse, antisocial behavior (conduct disorder), and the effects of HIV/AIDS. In a typical 3 month period in 2001, 187 "cases" were seen, of which 49 were new. There were 293 individual counselling sessions, 245 parent counselling sessions, and 50 family sessions. Groups for abused girls (30 girls in total), conduct disordered boys (40 boys), and the parents' support group (12 members) met regularly.

The funders arranged an external evaluation of the project in 1997. The evaluation noted that the project provided a cost-effective, accessible and appropriate alternative to professional mental health systems, and that its goals had been largely achieved. The evaluation resulted in a renewed cycle of funding.

Source: Prof. Brian Robertson

Advocacy for child and adolescent mental health

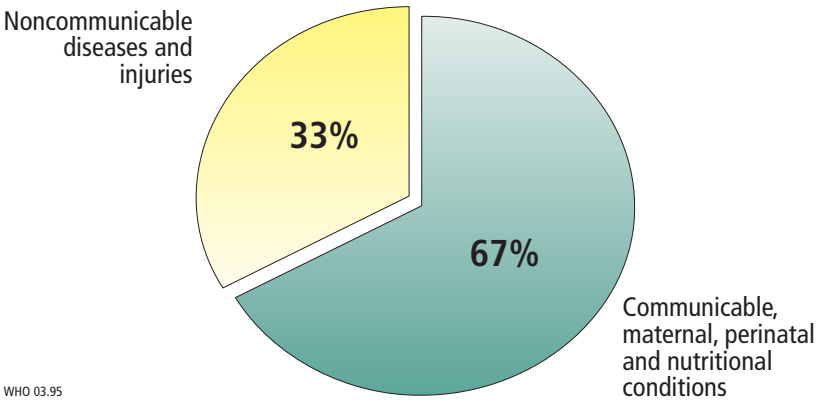
Advocacy for child and adolescent mental health has become the province of NGOs, parents and professional groups. In some instances, NGOs complement their advocacy with the support and provision of direct services. The parent movement has been particularly strong and increasingly focused on specific disorders. Professional groups in their advocacy have often focused on need for specific forms for care. The drawback to current advocacy is the fragmentation among NGOs and others in the development of co-ordinated systems of care, and discipline competition. The focus on particular disease entities can lead to imbalances in the provision of services which is particularly noteworthy in developing countries where programs for PTSD might be quite prominent, but where there is a lack of basic services for the diagnosis and treatment of depression, anxiety, and school related disorders.

Advocacy as an essential part of care for children and adolescents with mental disorders

- Effective advocacy requires support for the constituency of parents and providers.
- There is a set of skills and knowledge that can be disseminated to build advocacy networks in developing and developed countries.
- A key role for advocacy groups is monitoring the implementation of programs for quality and relevance.
- Advocacy groups can provide a structure within which a broad base of stakeholders can find a place for dialogue and action.

Source: Dr. Patt Franciosi/World Federation for Mental Health

Figure 2. **World: DALYs in 2000 attributable to main causes, 0-19 years, both sexes**



Recommendations

1. Due consideration of child and adolescent mental disorders should be incorporated into all WHO initiatives relating to either overall health or specific mental health.

   This is particularly relevant for the (i) development and dissemination of policy guidance, (ii) development of program guidelines, (iii) research projects and activities, and (iv) status reviews.

2. A Global Child and Adolescent Mental Health Action Plan should be established within the Department of Mental Health and Substance Dependence; it should support a balanced approach to care utilizing all appropriate means of treatment, and once established, its priorities should centre on:

   A. Contacting national health authorities over the next two years to (i) support the initiation of national plans for child and adolescent mental health, (ii) foster the capacity for advocacy building at the national level and (iii) provide guidance on how to increase the number of providers with child and adolescent mental health diagnostic and treatment skills.

   B. Documenting the adverse consequences of child and adolescent mental disorders in terms of: (i) the economic outcomes associated with child and adolescent mental disorders treated and untreated, (ii) exposure to violence, (iii) indicators of excess mortality attributable to child and adolescent mental disorders, and (iv) possible indicators modified from the DALYs measure, such as "days out of home".

   C. Identifying best practices on the use of psychopharmacologic agents with children and adolescents, and issuing authoritative guidelines on the rational use of psychotropic medication for this age group. Current data indicate that the indications for psychotropic medication use with children is limited. Countries need to address the "off-label" use of medications and establish oversight of psychotropic medication use with children and adolescents. Also, guidance for mental health services should recognize the special needs of children and adolescents including minimal standards.

   D. Identifying and disseminating information on examples of model programmes demonstrating how countries have increased capacity, utilized existing personnel, instituted re-training programs, improved outcomes etc.

3. Child and adolescent mental health specialists and centers of excellence with expertise in child and adolescent mental health should be identified on a country and regional basis, and included in an updated registry. Based upon this, a WHO Advisory Panel on Child and Adolescent Mental Health should be established.

4. WHO should establish, as part of its communication program, an interactive, high quality web-page that would serve as a world-wide focal point for the dissemination of information that could inform Ministers of Health of best practices, research findings, economic and epidemiological data, and consultative resources. This website should become an authoritative resource of public information for advocacy initiatives at the country level.

Meeting on Caring for Children and Adolescents with Mental Disorders: setting WHO directions

Geneva, 31 January – 1 February 2002

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