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1 Defining mental health and mental illness

Sharon Leighton and Nisha Dogra

Key features

- Discussion of the terminological confusion that exists in relation to issues associated with mental health.
- The scale of individual suffering from mental health problems and illness among young people.
- The worldwide phenomenon of the stigmatization of mental illness, originating during childhood.
- Evidence regarding interventions to reduce stigma.

Introduction

In this chapter we explore the concepts of mental health and mental illness from different perspectives, including those relating to children, and of children. This is important as those who work in mental health, or are familiar with the field, often make the assumption that the terms used are readily understood by others. The scale of the problem and access to services is outlined. We then discuss stigma generally, explore the reasons for it and possible sequelae, and then consider how this relates to children. Finally, interventions to reduce stigma are briefly presented. As mentioned in the Introduction, where possible we have referred specifically to the literature relating to children but where this is limited we have drawn from the wider literature to highlight key issues.

The chapter begins with an exercise which provides a practical context for the theoretical content and should be borne in mind as you read, and answered once you have finished the chapter.

Box 1.1
Exercise
General questions

- What words or images do you associate with the following terms:
  - Mental health
  - Mental health problems
  - Mental illness
  - Mental disorder
- What sorts of problems do people experience that could be described as mental health problems or mental illness?
- How would you be able to tell if someone was experiencing mental health problems or mental illness?

Case scenarios and associated questions

Please read each senario and then consider the following questions in relation to it:

- What do you think might be happening with the young person?
- Do you think the young person has a mental health problem or illness? If so, on what grounds would you justify that decision?
- Do they need help?
- If so, who and/or what might be helpful?
- How might this be helpful?

Case scenario 1

Jack, aged 9, lives with his mother and younger brother. His father unexpectedly left the family a year ago. Jack started a new school six months ago and is having difficulty settling in. He complains of tummy ache each school morning and is increasingly reluctant to attend.

Case scenario 2

Emily, aged 14, lives with her parents, who are both busy professionals. She works hard, achieves A-grades and plans to be a lawyer. Recently she has been teased by her friends about her weight and has decided to go on a strict diet. She is pleased with the results so far and plans to continue eating little, making herself sick after meals and exercising a lot.

Case scenario 3

Joshua, aged 15, lives with his dad and stepmother. He has little contact with his mum or younger brother and sister. Recently he has been cautioned by the police for joy-riding in stolen cars with his mates. He prefers to spend time smoking dope with older boys rather than going to school.

Defining mental health and mental illness

Clarity is essential when using the terms 'mental health' and 'mental illness'. In all phases of a recent small-scale research project, conceptual confusion was identified in the literature review and among participants (Leighton 2008). Ironically, referring to mental illness in terms of mental health originated in the 1960s in an attempt to reduce stigma (Rowling *et al*. 2002). There is no widely agreed consensus on the meaning of these terms and their use. Mental health and mental illness can be perceived as two separate, yet related, issues.

Ryff and Singer (1998) suggest that health is not a medical concept associated with absence of illness, but rather a philosophical one that requires an explanation of a *good life* – being one where an individual has a sense of purpose, is engaged in quality relationships with others, and possesses self-respect and mastery. This is synonymous with the World Health Organization (WHO) (2000, 2005b) definition of positive mental health.

However, such a definition is incomplete as individuals do not exist in isolation, but are influenced by, and influence, their social and physical environments. Furthermore, people will have their own individual interpretations of what a *good life* is. Rowling *et al*. (2002: 13) define mental health as the

capacity of individuals and groups to interact with one another and the environment in ways that promote subjective wellbeing, the optimal development and use of cognitive, affective and relational abilities, the achievement of individual and collective goals consistent with justice.

This is a more rounded definition, and one that can coexist alongside the WHO (1992) definition of mental disorder.

Mental health – one of many factors

It is also important to recognize that neither physical nor mental health exist separately – mental, physical and social functioning are interdependent (WHO 2004). Furthermore, all health issues need to be considered within a cultural and developmental context, as do the social constructs of childhood and adolescence (Walker 2005). The quality of a person's mental health is influenced by idiosyncratic factors and experiences, their family relationships and circumstances and the wider community in which they live (WHO 2004). Additionally, each culture influences people's understanding of, and attitudes towards, mental health issues. However, a culture-specific approach to understanding and improving mental health can be unhelpful if it assumes homogeneity within cultures and ignores individual differences (WHO 2004). Culture is only one, albeit important, factor that influences individuals' beliefs and actions (Tomlinson 2001; Dogra 2003). Interaction between different factors may lead to different outcomes for different individuals.

It can be argued that the above approaches are rooted in western perspectives. However, they provide a useful starting point from which to discuss mental health issues with children and their families.

Definitions of child mental health

Definitions of mental health as they relate specifically to children have been provided by the Health Advisory Service (HAS) (1995) and the Mental Health Foundation (1999). These definitions bear similarities to those provided by Ryff and Singer (1998) and Rowling *et al.* (2002), while recognizing the developmental context of childhood – i.e. the ability to develop psychologically, emotionally, creatively, intellectually and spiritually; initiate, develop and sustain mutually satisfying personal relationships; use and enjoy solitude; become aware of others and empathize with them; play and learn; develop a sense of right and wrong; and resolve problems and setbacks and learn from them (HAS 1995; Mental Health Foundation 1999). Such definitions are useful as they relate to '*societal*' expectations of children.

Different definitions are used to define mental ill health. The WHO uses the term 'mental disorders' broadly, to include mental illness, intellectual disability, personality disorder, substance dependence and adjustment to adverse life events (WHO 1992). The WHO acknowledges that the word 'disorder' is used to avoid perceived greater difficulties associated with 'illness' – for example, stigma and the emphasis on a medical model. Meltzer *et al.* (2000) use the term 'mental disorders' in reference to emotional, conduct, hyperkinetic and less common disorders as defined by the ICD (International Classification of Diseases) 10 and DSM (*Diagnostic and Statistical Manual of Mental Disorders*) IV. Jorm (2000) focuses specifically on depression and psychosis. Meanwhile, Rowling *et al.* (2002) use the terms 'mental illness' and 'mental disorder' interchangeably. Johns (2002) and the British Medical Association (BMA 2006) identify that the term 'mental health problems' is used to cover a broad spectrum of conditions ranging from diagnosable disorders such as anxiety and depression, through to acting out behaviours. The BMA (2006) also distinguish between mental disorders and illness, with illness being severe psychiatric disorders such as depression and psychosis.

Others take a broader view. Rickwood *et al.* (2005) refer to 'young people's help-seeking for mental health problems' and proceed to use various terms including 'psychological distress', 'mental health issues', 'mental health problems' and 'mental disorder'. The interchangeable use of these terms in effect renders them meaningless, as their use may reflect an individual's bias, or political correctness, rather than indicating the extent or severity of the problem. However, all identify alterations in mood, thinking and behaviour associated with distress or impaired functioning across various domains.

Entity or dimension?

Kendall (1988) presents the relative merits of using categories and dimensions with respect to mental disorders. Typically, medicine has used categories, given its roots in the biological sciences. Categorization allows for easier definitions, recognition if someone fits a particular category and therefore conformity with a clinical concept. However, a dimensions approach allows for greater flexibility. Kendall (1988) concludes that where psychotic illness is concerned a categorical approach may be preferable, whereas in other conditions the situation is more likely to be changeable, and would perhaps benefit from a dimensional perspective.

One way of distinguishing between distress associated with adverse life events and more severe disorders which involve physiological symptoms and underlying biological changes is to distinguish between mental health problems and mental illness, using a multi-dimensional model. This has an additional advantage in enabling normal 'distress' (e.g. grief following bereavement) to be recognized as part of the 'human condition', rather than being medicalized and possibly classed as 'depression'. It is suggested that a variety of normal human experiences have become medicalized through an ever increasing range of psychological disorders with virtually every type of behaviour eligible for a medical label (e.g. social phobia, over-eating disorder, dependent personality disorder) (Illich 1977; WHO 1992; American Psychiatric Association 1994).

Rowling *et al.* (2002) propose that mental health and mental illness can be seen to exist as part of a multi-dimensional model. An exemplar of mental health and mental illness being two separate and yet related continua can be found in the vulnerability-stress working model developed by Asarnow *et al.* (2001). This model suggests how the effects of ongoing stress on mental health can lead to mental illness (depression) if left unchallenged.

Depression is classed as a diagnosable disorder which is reported to be on the increase (WHO 1996). However, the term 'depression' is also employed in everyday language for a variety of states of distress: demoralization as a result of long-term suffering; living with chronic adversity and stress; reaction to loss; low self-esteem; and pessimistic outlook. While there are similarities between the feelings of unhappiness, despondency, frustration and sense of hopelessness associated with a state of emotional stress and with depression, the latter involves pervasive physical symptoms such as sleep and appetite disturbance, and, ultimately, changes in brain chemistry. However, the cut-off between what is 'normal' stress and what is depression may not always be clear. It is not just the presence of symptoms that defines a disorder but also its severity and pervasiveness as well as its impact on everyday functioning.

Thus, from a dimensional perspective, many features of mental disorder (psychosis excepted) can be viewed as part of the range of 'normal' human behaviour. For example, anxiety is a normal human response to the perception of danger. Different types of anxiety are developmentally appropriate during childhood – for example, separation is an issue for infants, academic performance can cause anxiety during middle childhood and peer rejection concerns adolescents (Moore and Carr 2000).

Mental health literacy

Finally, in this section, it is also worth considering how the mental health 'literacy' of adults and children in the general population varies from that of professionals. In all phases of a recent research project, conceptual confusion was identified in the literature review and among adolescent participants (Leighton 2006, 2008). Focus group participants did not find the single continuum model suggested by the WHO (2000) helpful (Leighton 2006). Furthermore, in the focus group feedback session, participants suggested that labelling serious mental illnesses such as schizophrenia and major depression, as 'mental health problems', diminishes the seriousness of mental illness, with implications for attitudes towards, and treatment of, those with mental illness (Leighton 2006). It is also evident that there is considerable confusion for young people between the terms 'mental health', 'mental illness' and 'learning disability' (Dogra *et al.* 2007; Rose *et al.* 2007).

However, whatever terminology is used, the scale of individual suffering from mental health problems and illness is significant, and this is now briefly outlined.

The scale of the problem

The number of people experiencing mental health problems worldwide is reported to have risen to nearly epidemic proportions, with depression identified as the leading cause of disability among 15–44-year-olds (WHO 1996). In the UK the prevalence of mental health problems among adolescents is high. One in 20 is reported to be experiencing mental health problems at any given time (Mental Health Foundation 1999; Meltzer *et al.* 2000; Coleman and Schofield 2005). The Office for National Statistics (ONS) survey carried out in 1999 identified the following prevalence rates of diagnosable mental disorder among 11–15-year-olds: depression 1.8 per cent; anxiety 4.6 per cent; conduct disorder 6.2 per cent (Meltzer *et al.* 2000). Moreover, the prevalence of serious mental illness increases greatly during adolescence (Davidson and Manion 1996; Smith and Leon 2001; Rickwood *et al.* 2005). Such problems have a negative impact on an individual's development across all areas of their lives – i.e. self-esteem, relationships, academic success, career options and lifestyle (Mental Health Foundation 1999; Meltzer *et al.* 2000). Furthermore, the burden of adolescent mental health problems and illness involves enormous financial costs to individuals, families and society. These include loss of earnings for parents and adolescents, and social care, health service, education and Home Office costs (Appleton and Hammond-Rowley 2000). Although the scale of the problem is vast, studies indicate that less than a fifth of young people who need mental health care actually receive any services and, of those who do receive services, less than half obtain services appropriate to their need (Atkins *et al.* 2003; Hinshaw 2005).

Stigma and mental illness

In this section the aim is to explore the concepts of, and the relationship between, stigma and mental illness. One possible reason for both conceptual confusion and reluctance to seek help is that the stigmatization of mental illness continues to be a worldwide phenomenon (Jorm *et al.* 1997; Crisp *et al.* 2000; Sartorius 2002; Gureje *et al.* 2005).

Definition of the concept of stigma

Stigma can be viewed as a social construct. Setting people apart from other members of society has a long history. In ancient Greece members of tainted groups – for example, slaves and

traitors – were branded with a mark (Goffman 1970; Hinshaw 2005). The concept is applied in diverse circumstances, including with reference to the mentally ill (Link and Phelan 2001). Additionally, stigmatization can be seen to depend on social, economic and political power and can occur on a large and tragic scale – for example, the systematic and dreadful stigmatization of the Jewish people by the Nazis (Link and Phelan 2001). Stigma was defined by Goffman (1970) as the position of the individual who is disqualified from full social acceptance. It is perceived as the outcome of a process of social labelling which singles out difference, names this difference inferiority, subsequently blames those who are different for their otherness and contributes to the creation of a spoilt identity (Goffman 1970). Since that seminal development, the concept has evolved. For example, stigma can be described with reference to the relationships between a set of interrelated concepts, rather than focusing solely on personal attributes – i.e. stigma exists when elements of labelling, stereotyping, separation, status loss and discrimination occur together in a power situation that allows these processes to happen (Link and Phelan 2001).

The nature and extent of stigmatization in adult mental illness

There are many factors involved in the formation of individuals' beliefs about mental illness, and their attitudes and behaviour towards those labelled as mentally ill. These include personal experience of mental illness, either personally or in someone known to them; the impact of the media; beliefs as to what causes mental illness (e.g. genetic, self-inflicted); and socio-cultural influences (Hinshaw 2005).

Four possible explanations for the stigmatization of mental illness have been identified in the research literature:

- dangerousness;
- attribution of responsibility;
- belief that mental illness is chronic with a poor prognosis;
- disruption of normal social interactions based on social rules (Hayward and Bright 1997).

These explanations can be elaborated as follows: people with mental illness are perceived as dangerous and unpredictable; there is an implied belief that the mentally ill choose to behave as they do and have only themselves to blame for their situation; people with mental illness are believed to respond poorly to treatment, and outcomes are poor, therefore they are an embarrassment and should be avoided; the mentally ill are seen as difficult to communicate with and this makes for unpredictable social intercourse. These are enduring themes, provoking personal fear in others and threatening to upset the status quo (Hayward and Bright 1997; Eminson 2004).

Explanations for the stigmatization of the mentally ill include the following ideas.

- From a biological perspective, a person suffering from mental illness may be viewed as a poor genetic choice in relation to reproductive potential and as a possible threat to the safety of the individual.
- The need to share understanding in order to survive as an individual and as a species means that when a person's way of perceiving the world is unfamiliar to us we can feel threatened and uncertain as to how to respond to them (Eminson 2004).

Media, mental illness and stigma

There is a dearth of research which focuses specifically on how mental illness is depicted in the children's and young persons' media (Wahl 2002). This is despite suggestions that such media

provide the means by which young people will derive a preliminary understanding of mental illness. Participants in a small-scale local study identified some positive and accurate representations in the media. These included the Jacqueline Wilson books, the film *A Beautiful Mind* and Channel 4 documentaries (Leighton 2006). Byrne (2003) discusses examples in soap operas when television can perform a major public service where care is taken over how mental illness is portrayed. One suspects that the converse is also true – that when care is not taken the damage done to those suffering with mental illness can be immense.

Two large-scale literature reviews have suggested that the media can be regarded as an important influence on community attitudes towards mental illness. It is considered that there is a complex and circular relationship between mass media representation of mental illness and public understanding, with negative media images promoting negative attitudes and resultant media coverage feeding off an already negative public perception. It is also thought that negative images will have a greater effect on public attitudes than positive portrayals (Francis *et al*. 2001; Edney 2004). Work by Wahl (2003) suggests that this is equally applicable to children.

Consequences of stigma

Stigmatization of the mentally ill is understood to be prejudicial to them, injurious to all aspects of their treatment in mental health services and damaging to their role as members of society (Hinshaw 2005). Stigmatization leads to individual and social discrimination against the stigmatized person. Several authors identify that the discriminatory behaviour displayed can be hostile or avoidant and that it operates throughout personal and social relationships, pervading the home, workplace, local community, health and social welfare systems. This can result in increased feelings of shame, increased personal and social impairment and isolation, perpetuation and worsening of an illness, reluctance to access health care and infringement of human rights (Link and Phelan 2001; Crisp 2004; Hinshaw 2005).

Children, mental illness and stigma

There is also a scarcity of research examining the issue of stigma in relation to children and mental illness (Wahl 2002; Hinshaw 2005). As described previously, the high prevalence of mental health problems in young people and their reluctance to access specialist services gives cause for concern. The indications are that children develop negative attitudes towards those with mental illness early on (Gale 2007). Additionally, adolescents are the adults of the future and therefore their beliefs and attitudes regarding mental health and illness will affect service development, the quality of life of those experiencing mental health problems and the help-seeking behaviour of individuals (Armstrong *et al*. 2000; Hinshaw 2005).

Box 1.2 highlights themes identified from work which focused on adolescents, mental illness and stigma, albeit to varying degrees and using different methods.

Box 1.2 Themes associated with mental illness and stigma identified by adolescents

- Negative attitudes towards groups described as deviant – for example, the mentally ill – were apparent by kindergarten and increased with age (Weiss 1986, 1994; Wahl 2002).

- Words and phrases used to describe people with mental health problems or mental illness were largely derogatory, with the most common labels being 'retarded', 'psycho(path)', 'spastic', 'mental', 'crazy' and 'nutter' (Bailey 1999; Pinfold *et al.* 2003).
- The most frequently cited causes of mental illness were stress, genetics and bad childhood experiences (Bailey 1999).
- Young people with experience of mental health problems described being met with negative attitudes and reactions from other people, including professionals (Scottish Executive 2005).
- Although adolescents stigmatized peers with both physical and mental illness, they had a greater tendency to stigmatize those experiencing a mental illness (Sessa 2005a, 2005b).
- Adolescents presenting in school with either a physical or mental illness were likely to be socially excluded, itself a risk factor for developing mental health problems (Sessa 2005a, 2005b).
- Providing mental health education could lead to a positive change in reported attitudes in the short term, especially among females and those reporting personal contact with someone who had a mental illness (Pinfold *et al.* 2003).
- Although adolescents with less knowledge about mental health and illness had more negative attitudes towards mental illness, this did not influence the willingness to seek help for mental health problems as much as other factors – for example, level of psychological distress, number of barriers to overcome in order to access help, or adaptability (Sheffield *et al.* 2004).

From the sparse literature available, it would appear that adolescents' attitudes towards mental illness tend to be negative and stigmatizing. The need for education among the public, and adolescents in particular, in order to combat the stigma of mental illness is highlighted in the literature (Davidson and Manion 1996; Armstrong *et al*. 1998; Esters *et al*. 1998; Bailey 1999; Secker *et al*. 1999; Taylor 2001; Naylor *et al*. 2002; Pow 2003; Hinshaw 2005; Sessa 2005b).

Early indicators from our own work in Nigeria are that such attitudes transcend culture (Dogra 2009). However, there is evidence that stigma can be tackled. We will now examine some of the interventions undertaken to reduce stigma among children.

Interventions to reduce stigma

Large-scale interventions, such as high profile campaigns, are often difficult to evaluate. In the UK there have been several such campaigns – for example, The Royal College of Psychiatrists' campaign, 'Every Family in the Land' (Crisp 2004) and the WHO 'Dare to Care' campaign (WHO 2001). There is little evidence available to indicate that these have successfully changed public or personal attitudes, although there is evidence that more targeted initiatives may reap benefits (WHO 2005a). While much of the work to date has focused on adults, there are increasing efforts to address the issue among younger populations.

There is scope for joint working between schools and child and adolescent mental health services (CAMHS) in order to provide mental health promotion and reduce stigma. However, it is important that we do not attempt to reduce stigma by just changing the terminology used, as there is no evidence that such strategies work.

One small-scale local study found that young people thought they might be helped by

having more basic information about local services (Dogra *et al.* 2007). In another such study, adolescents who lived with parental mental illness suggested that the best ways of providing adolescents with information about mental health included real experience and focusing on the issue in schools – i.e. existing sources of (mis)information. It was thought that those speaking out should be adolescents who were confident to talk about their situation, but they should not talk to people they knew for fear of being bullied and they should be pupils at other schools (Leighton 2006).

Two school-based interventions reported promising results. Rahman *et al.* (1998) concluded that the school programme they undertook was successful in improving mental health awareness in the children and their community. Unfortunately, the intervention is only briefly described and it is difficult to be clear whether attitudes towards mental health (and issues about stigma) were addressed, or whether awareness of mental health (and therefore knowledge and understanding) informed the intervention. More recently, Pinfold *et al.* (2003) undertook short educational workshops with 472 secondary school children in the UK. Changes were most marked for female students and those who had personal contact with people with mental health problems. Further analysis of the labels used to stigmatize people with mental illness found that of the 472 students sampled, 400 of them provided 250 words to describe a person with mental illness. Nearly half were derogatory (Rose *et al.* 2007). The authors conclude that there need to be interventions which address factual information about mental illness and that reduce the strong negative emotional reactions to people with mental illness. Effective evaluation is unlikely to be possible if there is no clarity about the purpose of the intervention or too many aspects covered in one evaluation (Naylor *et al.* 2002).

Summary

Considerable terminological confusion exists in relation to issues associated with mental health generally and among children and young people specifically. Furthermore, stigmatizing attitudes towards mental illness and related issues continue to pose a challenge. Children, young people and adults display similar negative attitudes towards both mental illness and individuals experiencing mental health problems or illness. However, there is some evidence that these might be amenable to interventions such as education.

You may now wish to reflect on the issues discussed in this chapter by returning to the exercise in Box 1.1.

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