

SAMPLE CHAPTER FROM:

Psychosis and Schizophrenia in Children and Young People

The NICE Guideline on Recognition and Management

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2 PSYCHOSIS AND SCHIZOPHRENIA IN CHILDREN AND YOUNG PEOPLE

This guideline is concerned with the recognition and management of psychosis and schizophrenia in children and young people up to the age of 18. The term 'psychosis' is used in this guideline to refer to the group of psychotic disorders that includes schizophrenia, schizoaffective disorder, schizophreniform disorder and delusional disorder as identified by the *International Classification of Diseases – 10th revision (ICD-10; World Health Organization, 1992)*. This guideline also addresses the population of children and young people considered clinically to be at high risk or prodromal for psychosis and schizophrenia. It does not address the identification and management of other psychotic disorders, such as bipolar disorder and unipolar psychotic depression, or schizophrenia in adults, because they are covered by other NICE guidelines.

2.1 THE DISORDER

2.1.1 Symptoms, presentation and patterns

Psychosis and the specific diagnosis of schizophrenia in children and young people represent a major psychiatric disorder, or cluster of disorders, characterised by psychotic symptoms that alter the child or young person's perception, thoughts, mood and behaviour. The symptoms of psychosis are usually divided into 'positive symptoms', including hallucinations (perception in the absence of any stimulus) and delusions (fixed or falsely held beliefs), and 'negative symptoms' (such as emotional apathy, lack of drive, poverty of speech, social withdrawal and self-neglect). Children and young people who develop psychosis will have their own unique combination of symptoms and experiences, the precise pattern of which will be influenced by their circumstances and stage of development.

Typically, in child and adolescent-onset psychosis and schizophrenia there is a prodromal period characterised by some deterioration in personal functioning, which may follow an acute period of stress, a distressing experience or physical illness (Garralda, 1984a). The prodromal period includes negative symptoms such as concentration and memory problems, unusual or uncharacteristic behaviour and ideas, unusual experiences, bizarre perceptual experiences, disturbed communication and affect, social withdrawal, apathy and reduced interest in daily activities. This period can last up to 1 year (Werry *et al.*, 1994) and negatively affect school performance. The insidious pattern of onset can delay the diagnosis of psychosis and schizophrenia in children.

The prodromal period is typically followed by an acute episode marked by the positive symptoms of hallucinations and delusions, and behavioural disturbance.

These symptoms are usually accompanied by agitation and distress (NCCMH, 2010). A wide range of anomalous perceptual experiences may occur at the onset of an episode of psychosis leading to a sense of fear or puzzlement, which may constitute a delusional mood and herald a full psychotic episode. These anomalous experiences may include the sense that familiar places and people and their reactions have changed in some subtle way. These experiences may result from a breakdown between perception and memory (for familiar places and people) and associated affective responses (salience given to these perceptions). These experiences may be frightening, confusing and distressing for the child or young person. For example, a child or young person at the onset of illness may study their reflection in the mirror for hours because it looks strangely unfamiliar, misattribute threatening intent to an innocuous comment or experience family members or friends as being unfamiliar, leading to a secondary delusional belief that they have been replaced by doubles or aliens. In summary, some clinical phenomena in psychosis and schizophrenia can be understood in terms of a loss of normal contextualisation and coordination of cognitive and emotional processing. Following resolution of the acute episode, commonly after pharmacological and psychological interventions, the positive symptoms diminish and disappear for many children and young people, although a number of negative symptoms may remain. This phase, which can last for years, may be interrupted by recurrent acute episodes that may need additional intervention. Persisting symptoms appear to be especially common when the condition starts in pre-adolescent children (Eggers & Bunk, 1997).

2.1.2 At risk mental states

In recent years there has been a growing emphasis on early detection and intervention in order to delay or possibly prevent the onset of psychosis and schizophrenia. This focus on very early intervention and prevention has stimulated an interest in identifying, and potentially intervening in, the so-called 'at risk mental states' (or prodrome) which may precede the onset of the disorder (see Section 2.8.4).

At risk or 'ultra-high risk' mental states, are characterised by help-seeking behaviour and the presence of attenuated (subclinical) positive psychotic symptoms, brief limited intermittent psychotic symptoms or a combination of genetic risk indicators, such as the presence of schizotypal disorder, with recent functional deterioration. Although the risk for schizophrenia emerging over a 12-month period appears to be increased in these children and young people (between one in five to one in ten may be expected to develop a schizophrenic disorder, Ruhrmann *et al.*, 2010), it remains the case that prediction of schizophrenia based on at risk or ultra-high risk mental states is modest given that the majority of those identified do not become psychotic. Furthermore, most children and young people identified with at risk mental states have a mixture of other mental health problems (for example, depression, anxiety, substance-use disorders or emerging personality disorder) requiring a range of targeted interventions. In addition, the potential use of a clinical label that conveys a future risk of psychosis or schizophrenia raises ethical issues and may itself be perceived

as stigmatising. It may be that at risk or ultra-high risk mental states are best viewed as a dimension rather than a diagnostic category, including at one extreme children and young people with non-specific symptoms and at the other those on the cusp of psychosis. Finally, given the low rate of transition to psychosis, any interventions used must benefit (and not harm) the majority of children and young people (false positives) who do not develop psychosis.

2.1.3 Impairment and disability

Impairments associated with psychosis and schizophrenia include the consequences of living with disabling psychotic symptoms, the adverse effects of drug treatments and poor physical health (see Section 2.1.6) and stigma (see Section 2.6). Impairment can affect a child or young person's psychological, social and educational development and functioning. While about one fifth of children and young people with schizophrenia have a good outcome with only mild impairment, at the other extreme about a third are severely impaired requiring intensive social and psychiatric support (Hollis, 2000). The onset of schizophrenia in childhood and adolescence results in greater impairment than when schizophrenia first presents in adulthood (see Section 2.1.4). This is in part because the nature of the disorder is more severe in children and young people, but also because the onset of schizophrenia during childhood disrupts social and cognitive development. Social functioning, in particular the ability to form friendships and love relationships, appears to be very impaired in early-onset schizophrenia. Impairment affecting families can also be considerable, creating distress and disharmony in social interactions and relationships. For young adults, impairment is also seen in their working lives. Since children and young people with psychosis and schizophrenia have greater cognitive, psychological and social impairments, early recognition and intervention is crucial.

2.1.4 Prognosis, course and recovery

Schizophrenia in children and young people characteristically runs a chronic course, with only a minority making a full symptomatic recovery from the first psychotic episode. The short-term course for schizophrenia is worse than for other psychotic disorders in children and young people, with only 12% in full remission at discharge compared with 50% of children and young people with affective psychoses (Hollis & Rapoport, 2011). The short-term outcome for schizophrenia presenting in early life appears to be worse than that for adults with a first episode of psychosis (Robinson *et al.*, 1999a). If full recovery does occur then it is most likely to happen within the first 3 months of onset of psychosis. Early recovery appears important in determining outcome. Young people with schizophrenia who have psychotic symptoms after 6 months have only a 15% chance of their symptoms achieving full remission, while over half of all those who make a full recovery have active psychotic symptoms for less than 3 months (Hollis & Rapoport, 2011).

A recent Israeli whole population study found that people with schizophrenia who were younger than 17 years had a poorer outcome overall, with longer length of initial hospital stay, more readmissions and more hospital days per year than young people aged 18 or older (Rabinowitz *et al.*, 2006). Schizophrenia is also frequently associated with significant impairments in many aspects of life including social, educational, vocational and familial. It is also associated with increased morbidity and mortality through both suicide and natural death.

The predictors of poor outcome in child and adolescent-onset psychoses include premorbid social and cognitive impairments, a prolonged first psychotic episode, extended duration of untreated psychosis (DUP) and the presence of negative symptoms. Premorbid functioning and negative symptoms at onset of psychosis provide better prediction of long-term outcome than categorical diagnosis (Hollis & Rapoport, 2011) using ICD-10 or *Diagnostic and Statistical Manual of Mental Disorders – 4th edition* (American Psychiatric Association, 1994; DSM-IV).

Even though some children and young people never experience a complete recovery from their psychotic illness, they still manage to sustain an acceptable quality of life if given adequate support and help. Recovery is a fundamentally personal process that involves finding a new sense of self and feeling of hope, and it also requires appropriate external, material and psychosocial conditions that can facilitate the process (Kogstad *et al.*, 2011).

2.1.5 Diagnosis

This guideline is concerned with both the broader category of psychosis (including schizoaffective disorder, schizophreniform disorder, delusional disorder and schizophrenia) and with the narrower diagnosis of schizophrenia in children and young people. However, as a full discussion of the issues of the diagnosis of psychosis and schizophrenia is outside the scope of this guideline, specific issues relating to children and young people are described here.

The experience of a psychotic disorder challenges an individual's fundamental assumption that they can rely upon the reality of their thoughts and perceptions. This is often both frightening and emotionally painful for both the person with psychosis and for those close to them. Having this experience classified as a disorder, and acquiring a diagnostic label, may either be helpful in facilitating understanding or may be experienced as yet a further assault upon their identity and integrity. Professionals need to be aware of both the positive and negative impacts of discussing a diagnosis, especially in children and young people. This has led to some professionals and service user/carer groups questioning the usefulness of the diagnosis and instead preferring to emphasise a narrative formulation of the individual's experiences.

The current concept of schizophrenia in children and young people evolved from a different perspective held during much of the 20th century. Until the early 1970s the term 'childhood schizophrenia' was applied to children who would now be diagnosed with autism. Kolvin's landmark studies distinguished early onset (autistic)

children from those with a relatively 'late onset' psychosis that closely resembled schizophrenia (Kolvin, 1971; Kolvin *et al.*, 1971). Importantly, in DSM-III (American Psychiatric Association, 1980) and ICD-9 (World Health Organization, 1975) the separate category of childhood schizophrenia was removed, and the same diagnostic criteria for schizophrenia were applied across the age range. Major additional evidence for the validity of the diagnosis of schizophrenia in childhood and adolescence comes from the Maudsley Child and Adolescent Psychosis Follow-up Study (Hollis, 2000). A DSM-III-R (American Psychiatric Association, 1987) diagnosis of schizophrenia in childhood and adolescence predicted a significantly poorer adult outcome compared with other non-schizophrenic psychoses and a diagnosis of schizophrenia showed a high level of stability—80% had the same diagnosis at adult follow-up (Jarbin *et al.*, 2003).

Both ICD-10 and DSM-IV describe similar symptom clusters necessary for a diagnosis of schizophrenia (see Section 2.1.1). ICD-10 requires that these be present for 1 month while DSM-IV requires a total duration of 6 months. But this difference is less marked when one considers that ICD-10 refers to acute positive symptoms only, while DSM-IV includes any period of non-specific impairment or attenuated (subclinical) symptoms that may precede an acute episode. In both DSM-IV and ICD-10, evidence of deteriorating and impaired functioning in addition to persistent psychotic symptoms is essential for a diagnosis. Isolated psychotic symptoms (typically auditory hallucinations) without functional impairment are surprisingly common in children (definite psychotic symptoms are found in 6% of 11 year olds in the general population) (Horwood *et al.*, 2008) and should not be confused with a diagnosis of psychosis or schizophrenia, which is very rare in pre-pubertal children.

The majority of children and young people for whom a diagnosis of psychosis or schizophrenia is being considered will be in their first episode of illness. The future natural history and diagnostic stability of an initial psychotic episode shows much variation. However, when an ICD-10 or DSM-IV diagnosis of schizophrenia can be made (particularly when accompanied by insidious onset and early presentation of negative symptoms) the greater is the likelihood of diagnostic stability (Hollis, 2000). There is therefore a tension between not wishing to be precipitately deterministic in diagnosis and prognosis but also wishing to give as accurate a prediction of likely future course as possible.

While the much less specific umbrella term 'psychosis' has therefore found increasing favour by some professionals and by some service user and carer groups, it should only be used in those instances where criteria for more specific ICD-10 and DSM-IV diagnoses of schizophrenia or schizophreniform psychosis are not fulfilled. Indeed recent findings suggest that a formal diagnosis of schizophrenia can be made in a large proportion of children and young people presenting with multiple features of a psychotic illness (Coentre *et al.*, 2011). Stigma towards schizophrenia among clinicians, together with overly pessimistic views of outcome and the likelihood of recovery, may prevent clinicians from openly and honestly sharing a diagnosis with young people and their families.

2.1.6 Physical healthcare

Children and young people with psychosis and schizophrenia can expect poorer physical health than the general population as they get older, with life expectancy reduced by 16 to 25 years (Brown *et al.*, 2010; Parks *et al.*, 2006). While suicide or injury cause a third of these premature deaths, two thirds result from cardiovascular, pulmonary and infectious diseases (Brown *et al.*, 2010). These issues are discussed in the *Schizophrenia* guideline for adults (NCCMH, 2010). However schizophrenia in children and young people tends to be a more disabling and persistent disorder (Hollis, 2003), bringing with it greater vulnerability to physical harm from both the condition and its treatments.

Given that cardiovascular disease is the main cause of reduced life expectancy, the question arises whether there are potentially modifiable precursors operating in children and young people with schizophrenia? The major candidates are smoking, obesity, dyslipidaemias, glucose intolerance and hypertension. These factors are interdependent. For example, the link between childhood obesity, dyslipidaemias, glucose intolerance, hypertension and vascular abnormalities is conclusive (Weiss *et al.*, 2004), explaining why childhood obesity increases coronary heart disease in adulthood (Baker *et al.*, 2007).

Evidence that children and young people with schizophrenia are exposed to these risks comes mainly from antipsychotic treatment studies where such impacts may be even more important given that these drugs are prescribed for lengthy periods over a critical developmental phase. Only one paediatric cohort study has examined this issue in children and young people treated for the first time with antipsychotics (Correll *et al.*, 2009). This revealed high prevalence and rapid onset (within 12 weeks) of weight gain in all antipsychotics investigated (aripiprazole, olanzapine, quetiapine and risperidone). Metabolic disturbances were also observed in olanzapine, quetiapine and risperidone, but not aripiprazole. Changes in weight gain in those taking risperidone were dose related, whereas only adverse metabolic effects were dose related with olanzapine, and no dose relationship was observed with aripiprazole and quetiapine. This landmark study included children and young people aged 4 to 19 years with various mental disorders including schizophrenia and its findings have been reinforced by two systematic reviews (De Hert *et al.*, 2011; Fedorowicz & Fombonne, 2005). A systematic review confined to schizophrenia in children and young people observed that while antipsychotics had similar efficacy, adverse effects varied between drugs (Kumra *et al.*, 2008b). Overall, children and young people appear more vulnerable than adults to side effects of antipsychotic medication (weight gain, extrapyramidal symptoms [EPS], metabolic problems, prolactin elevation and sedation).

Studies of first episode psychosis provide insights into a treatment-naïve young group, mostly in their late teens and 20s, and encompassing the under 18s (for example, Kirkbride *et al.*, 2006). A systematic review of weight gain and cardiometabolic abnormalities (Foley & Morley, 2011) revealed that there was no difference in weight gain, blood pressure (BP) and cardiometabolic indices between people with a first episode and controls before starting antipsychotics. However, within 8 weeks of first exposure, heightened cardiovascular risk was apparent and worsened over the next 12 months.

No significant differences separated first- and second-generation antipsychotics but variance in adverse effects was evident within each class of drugs. For instance, weight gain after 12 months with olanzapine far exceeded ziprasidone among the second-generation 'atypical' antipsychotics. Over a third of those with a first episode experienced metabolic disturbance within 8 months of commencing treatment (Curtis *et al.*, 2011). It should also be noted that occasionally diabetes and dyslipidaemia have been observed in the absence of weight gain, which underlines the clinical importance of being alert to the possibility of serious metabolic disturbance in those taking antipsychotic medication who have not gained weight (McIntyre *et al.*, 2001).

The association between antipsychotics and weight gain is well established and a substantial number of children and young people with emerging psychosis experience aggressive early changes in weight and cardiometabolic risk. Their vulnerability to future physical ill health is further explained by concomitant lifestyle issues, particularly tobacco use.

While smoking rates in the UK general population fell from 39% in 1980 to 25% in 2004, rates for people with schizophrenia continued at about 70%, suggesting they have failed to benefit from the effective prevention of the most potent cause of premature death (Brown *et al.*, 2010). Understanding how smoking develops is vital to reducing harm. Myles and colleagues (2012) found that 59% of people with first-episode schizophrenia used tobacco at presentation, a rate six times higher than that in comparable non-psychiatric populations. Furthermore, in the general population 66% of current and past tobacco users started smoking before the age of 18 (Health and Social Care Information Centre, Lifestyles Statistics, 2010) while very few commence smoking after their early 20s (Amos *et al.*, 2009). Thus tobacco use in children and young people with psychosis and schizophrenia is a substantial problem which continues into adult life.

Poor physical health is not just experienced through illness or premature death. Severe weight gain may lower self-esteem, contribute to discrimination and lead to treatment non-compliance, already problematic in the adolescent population (Hack & Chow, 2001). Other metabolic side effects such as hyperprolactinaemia (causing menstrual disturbances, sexual dysfunction and galactorrhoea) can similarly distress young people (Fedorowicz & Fombonne, 2005). Although antipsychotic selection may mitigate such effects, the distress evoked requires sensitive clinical practice.

In summary, precursors of future cardiovascular disease threaten substantial numbers of children and young people with emerging psychosis and schizophrenia. Previously unexposed to antipsychotics, this group are particularly vulnerable to weight gain and cardiometabolic disturbances (Correll *et al.*, 2009; Foley & Morley, 2011; Álvarez-Jiménez *et al.*, 2008). Although antipsychotics vary in their propensity to induce weight gain and cardiometabolic disturbance, these effects may be caused by any antipsychotic, whether typical or atypical, occur frequently and appear within weeks of starting treatment (Correll *et al.*, 2009; Foley & Morley, 2011). Notwithstanding the adverse metabolic effects of antipsychotics, children and young people with psychosis and schizophrenia often experience multiple cardiovascular risk factors, including poor nutrition, inadequate exercise and problematic tobacco and substance use, compounded by poor healthcare (Varley & McClennan, 2009).

2.2 INCIDENCE AND PREVALENCE

Schizophrenia is very rare in pre-pubertal children (Burd *et al.*, 1987; Gillberg, 1984; Gillberg & Steffenburg, 1987) and there is limited epidemiological knowledge on this early onset disorder. From the information available it has been estimated that the prevalence of childhood schizophrenia may be 1.6 to 1.9 per 100,000 child population (Burd & Kerbeshian, 1987; Gillberg, 1984 and 2001; Hellgren *et al.*, 1987). However, its prevalence increases rapidly from age 14 onwards (Gillberg *et al.*, 1986; Thomsen, 1996) with a peak incidence in the late teens and early 20s. In an Australian sample of first episode psychosis, a third of those newly diagnosed were aged between 15 and 19 years old (Amminger *et al.*, 2006). While male gender predominance has been described in pre-adolescent children (Russell *et al.*, 1989), an equal gender ratio is more commonly reported in adolescence (Hollis, 2000).

2.3 POSSIBLE CAUSES OF SCHIZOPHRENIA

Psychosis and schizophrenia in children and young people appears clinically and biologically continuous with the adult-onset disorder. In common with schizophrenia in adults, the possible causes of schizophrenia in children and young people are not well understood. No single cause has been identified. Increasingly, it is thought that schizophrenia results from a complex interaction of genetic, biological, psychological and social factors, as described briefly below.

Much of the research into the causes of schizophrenia has been based on adult populations and is consistent with a stress-vulnerability model (Zubin & Spring, 1977). This model suggests that anyone could experience psychotic symptoms if placed under sufficient stress, but that people vary in their level of vulnerability to developing psychosis due to individual differences, which may be genetic, social, physiological or psychological. The model proposes that whether or not an individual develops psychosis is dependent on the interaction between their pre-existing vulnerability and stressful events. There is good reason to think that such a model can be applied to children and young people as well as adults. Research has attempted to determine what kinds of vulnerability and what types of stressors are most closely linked to the development of schizophrenia and other psychoses.

Twin studies have shown that schizophrenia results from interplay of genetic and environmental factors. Parental schizophrenia increases the risk in children, especially if both parents are affected (Gottesman *et al.*, 2010) and/or if children grow up in poor rearing environments within suboptimally functioning or otherwise disturbed families (Wahlberg *et al.*, 1997). However, we still know relatively little about which specific genes or environmental factors are involved and how these factors interact and actually cause psychotic symptoms. Because there are likely to be multiple genes involved, the genetics of schizophrenia is moving away from the notion of finding a single major gene for the disorder, towards a search for genes that confer susceptibility or vulnerability traits. Studies of pre-pubertal children with schizophrenia have also found a high rate (up to 10%) of various cytogenetic abnormalities including

small structural deletions or duplications that disrupt genes (Eckstrand *et al.*, 2008; Rapoport *et al.*, 2005; Walsh *et al.*, 2008).

The search for environmental factors includes perinatal risk factors (for example, birth complications, nutrition, infections, child abuse and neglect, early cannabis use in adolescence and stressful life events. Read and Sanders (2010) propose that the vulnerability described in the stress-vulnerability model need not be the result of a genetic vulnerability but can be caused by difficult childhood events. They point to numerous studies illustrating that factors like urban living, poverty and child abuse are highly predictive of later psychotic symptoms with or without a genetic predisposition (Read *et al.*, 2008). There is evidence of a dose–response association between childhood trauma and psychosis, which suggests a causal relationship with childhood trauma. Therefore in order for effective treatment and recovery to occur it is imperative to routinely enquire about traumatic experiences and offer psychosocial treatments to those who report such events (Larkin & Read, 2008).

Cannabis use in adolescence has been shown to have a strong association with onset of psychosis and schizophrenia in adult life (Arseneault *et al.*, 2002). It has not been directly implicated in child and adolescent onset schizophrenia, possibly because of the relatively lower prevalence of cannabis use in younger adolescents and a short duration between exposure and psychotic outcome. However, cannabis use is associated with earlier age of onset of schizophrenia in adults (Arendt *et al.*, 2005). Current thinking suggests that cannabis may enhance the risk of schizophrenia in vulnerable individuals during a critical period of adolescent brain development.

2.4 ASSESSMENT

2.4.1 Pre-pubertal children

The prevalence of psychosis and schizophrenia in pre-pubertal children is very low (Burd *et al.*, 1987; Gillberg, 1984; Gillberg & Steffenburg, 1987), which means that only those clinicians working in specialist tertiary centres are likely to see sufficient numbers of children to have developed skills in assessment and diagnosis. The diagnosis of schizophrenia is to a large extent based on the effective communication by the child to others of a mixture of unusual subjective mental experiences, poor integration of sensory, emotional and cognitive experiences and bizarre behaviour. Young children's ability to integrate and communicate these experiences develops gradually before puberty, making the diagnosis of psychosis more difficult than in young people or adults and is more likely to be based on behaviour than subjective experiences.

Very early onset schizophrenia shows a high rate of insidious development (Ropcke & Eggers, 2005) over 6 months (Gordon *et al.*, 1994), with a mean age at onset of 6.9 years (range of 3 to 11 years). The majority of children display pre-morbid psychiatric disturbance (Russell *et al.*, 1989), most commonly attention deficit hyperactivity disorder (ADHD), conduct problems (with aggression, truancy and firesetting) and developmental abnormalities within the autistic spectrum (present in 1 in 4, 26%). Early diagnostic stages can take some time to resolve; in children presenting

with a possible diagnosis of psychosis and schizophrenia, the latter is confirmed in about half (Remschmidt *et al.*, 2007). Services need to be configured to facilitate early detection and treatment.

A mental health assessment helps in the formulation of the problem, identifying strengths and weaknesses, risks and needs. The assessment of a child should provide an understanding of the presenting problem within the social context of their life, both past and present, and facilitate the development of a care plan that addresses their broad range of needs, including social, educational and health needs. Assessment should include mental state, physical examination and a detailed developmental history, paying particular attention to pre-morbid functioning (Hollis, 2008). Abnormal premorbid functioning is more common than in adult onset disorder or non-schizophrenic psychoses starting in childhood and adolescence (Hollis, 2003; Hollis, 1995; Jacobsen & Rapoport, 1998) and is associated with negative symptoms (Hollis, 2003) and may be a predictor for poor prognosis (Hollis, 2000; Werry & McClellan, 1992; Vyas *et al.*, 2007).

The child's cognitive level will influence their ability to both express and understand complex psychotic symptoms and subjective experiences like hallucinations (Hollis, 2008; Ropcke & Eggers, 2005). An understanding of the child's cognitive functioning and whether they have speech or language problems will aid the clinician in teasing out the developmental issues from core psychotic phenomenon. Hallucinations in children are more frequently described as being internally located making it difficult to distinguish such experiences from inner speech or thoughts (Garraalda, 1984a & b). The clinician needs to distinguish true hallucinations from normal subjective phenomena such as dreams or imaginary friends (Hollis, 2008).

Delusions are less frequent than in adolescent or adult schizophrenia and are likely to be less systematised. Formal thought disorder may be difficult to distinguish from immature language development with apparent loosening of associations and illogical thinking. Negative symptoms can appear very similar to non-psychotic language and social impairments, and can be confused with anhedonia or depression (Hollis, 2008).

Assessing a child's mental state can be a complex process. Understanding the child's development and whether they have speech and language problems or a learning disability will affect this assessment and what conclusions can be drawn from it. Clinicians may need to observe the child in a variety of settings to help clarify the diagnosis. Inpatient or day care services provide an opportunity to observe the child over a period of time, which can assist in providing a comprehensive and detailed mental state assessment. Engagement with the child and gaining their confidence may require a number of meetings. Assessment should also include a full mental health assessment to identify comorbid conditions—onset of schizophrenia in childhood can coexist with pervasive developmental disorder (Rapoport *et al.*, 2009). Multidisciplinary assessment is beneficial in providing a holistic view of the child's needs. Baseline psychometric testing can be helpful in assessment and for future educational planning.

Given the rarity of very early onset psychosis and schizophrenia it is important that organic illness is excluded. Physical healthcare and baseline investigations

should include detailed physical examination and blood tests. Magnetic resonance imaging (MRI) brain scanning may be considered in more complex presentations, electroencephalogram (EEG) if seizures are suspected and referral for a neurological opinion if neurodegenerative disorders are indicated (Hollis, 2008). Genetic testing (including consultation with a clinical geneticist) could be considered given reports of genetic abnormalities in one cohort of childhood-onset schizophrenia reaching 10% (Eckstrand et al., 2008). A careful differentiation needs to be made between children with psychotic states and those with what is sometimes called multiple complex developmental disorder or multiple developmental impairment, when children present with brief psychotic symptoms, inappropriate affect and mood lability, poor interpersonal skills in spite of normal social skills, thought disorder (bizarre, disorganised thinking) and impaired sensitivity to social stimuli (Kumra et al., 1998), but not the full schizophrenic presentation. While the long-term risk for development of schizophrenia is increased in these children, the majority will not develop the disorder in the short term.

2.4.2 Young people

The assessment of young people thought to be experiencing an emerging or frank psychotic disorder will vary according to the route they have taken to the healthcare professional. Some young people will present themselves seeking help for their distress, impairment or abnormal experiences, while others will be unwilling participants who are referred or presented for assessment by someone else (a parent or carer or possibly a teacher). In either scenario engagement of the young person is crucial both to assessment and to subsequent intervention.

The assessment needs to be flexible and adapted to the young person's age and developmental level in terms of setting, language and the style of interviewing. Empathic and curious enquiry regarding the young person's current life situation, concerns and predicaments should usually be the starting point. However, this will need to progress to a more comprehensive account of a young person's global functioning and developmental history in order to reach any formulatory or diagnostic understanding.

Assessment needs to encompass careful enquiry about core symptomatology, particularly of abnormal belief systems, perceptions, thoughts and experiences. Physical health factors and a physical examination should not be overlooked (see Section 2.1.6). The role of substance use as both a causative and a comorbid or exacerbating factor requires careful exploration (see Section 2.3). Risks both to the individual and to others need to be assessed but also placed carefully within the developmental stage of adolescence where a degree of risk taking is both normal and necessary for individuation.

Psychosis in childhood or adolescence may result from an organic neuropsychiatric cause such as encephalitis, temporal lobe epilepsy, cerebral lupus, drug intoxication and rare neurodegenerative conditions such as Wilson's disease and adrenoleukodystrophy. The index of suspicion of an organic cause is increased when there are positive neurological signs, autonomic disturbance and fluctuating levels of consciousness. In

such cases physical investigations such as blood tests, EEG and an MRI or computed tomography (CT) scan may be helpful in reaching a diagnosis.

Physical investigations are also indicated before starting antipsychotic drug treatment. These include measuring height, weight, pulse, blood pressure and depending on the drug, an electrocardiogram (ECG) and baseline lipids, prolactin and glycosylated haemoglobin (HbA_{1c}).

Collateral information from parents and carers (particularly historical information) and from schools also forms an important part of assessment. The failure of a young person to make expected progress (personal, social or academic) is as significant a marker of impairment and deterioration as is the loss of previously gained skills or competencies by an adult.

Semi-structured interview tools can be a useful adjunct to clinical assessments, providing prompts for less commonly experienced symptoms and setting a benchmark for future improvement (or deterioration) in symptoms or functioning.

2.5 ENGAGEMENT, CONSENT AND THERAPEUTIC ALLIANCE

Children and young people with schizophrenia and psychosis, together with their families and those close to them, can face times of significant distress. This can be especially so during acute phases, when the individual might exhibit fear, agitation, suspicion or anger in ways that can be confusing and alarming. Successful engagement in both the short and long term is the foundation of subsequent psychosocial and pharmacological interventions and interventions aimed at addressing physical health. Early engagement is crucial as delays in receiving treatment have been shown to have a detrimental effect on longer term outcomes (The NHS Confederation, 2011).

Engaging a child or a young person with these experiences may at times require considerable persistence and flexibility from professionals. *The Early Psychosis Declaration* highlights the need to ‘reduce the long delays and coercive engagements that many families experience by services working better together and much earlier to meet the specific needs of young people and their families’ (Rethink, 2004). Engaging the child or young person and their parents or carers may be made more challenging if they do not share the professionals’ view of what the main problems are, the nature of the diagnosis and the need for treatment.

One barrier to engagement might be the potential challenge of an implied or future diagnosis for individuals considered to be ‘at risk’ of developing psychosis or schizophrenia (see Section 2.1.2) and offered or receiving services from an early intervention in psychosis (EIP) team.¹ Given that the development of psychosis in these circumstances is a possibility rather than a certainty, the clinical value of focusing on an at risk mental state needs to be balanced against the need to address the presenting problems in order to create a therapeutic alliance.

¹At time of publication, EIP services are only available in England

Psychosis can have a profound effect on an individual's judgment and their capacity to understand their situation and consent to specific interventions. To support the child or young person in giving informed consent with regards to decisions about their care, the *Mental Capacity Act 2005* (Her Majesty's Stationery Office [HMSO], 2005; Department for Constitutional Affairs, 2007) can be used as a guide for those aged 16 and over, and 'Gillick competence' can be used for those aged under 16. However, depending on the level of risk, refusal to accept treatment in those under 16 may be overruled by parental authority or at any age by the *Mental Health Act 2007*² (HMSO, 2007).

An important consideration is the requirement to manage children and young people with psychosis and schizophrenia in low-stigma and age-appropriate settings (The NHS Confederation, 2011), and to provide information that is age appropriate (Department of Health, 2010) and supports the individual and their family in making informed decisions about treatment (Department of Health, 2011a).

Effective engagement for children and young people with psychosis and schizophrenia might be supported by minimising disruptive, developmentally inappropriate transitions. For example, although EIP patients have to be transitioned after 3 years, it makes little sense to have to transition a young person who entered an EIP service at age 14 to CAMHS at age 17 for 1 year. Services need to adapt to developmental needs as well as targeting specific disorders by supporting mental health across the life cycle, developing youth-focused mental health services stretching from childhood into adulthood, and utilising the expertise of both child and adult services (Rethink, 2011). How this is achieved in practice has particular relevance to this guideline.

2.6 LANGUAGE AND STIGMA

Psychosis and schizophrenia are among the most stigmatised mental health problems and people with these conditions are often stereotyped as dangerous and unpredictable (Thornicroft *et al.*, 2009). Studies have shown that the public and mental health staff express a desire for social distance from people with psychosis (Corrigan *et al.*, 2002). Stigma has been described by service users as more disabling than the mental health problem itself, resulting in a second 'illness'. Other psychological conditions such as depression, social anxiety and low self-esteem may occur as a direct consequence of stigma. Internalised or 'subjective' stigma encompasses the idea that those with mental health problems internalise public stereotypes and experience both shame of their diagnosis and fear of discrimination. Stigma and discrimination associated with psychosis can discourage people from seeking help, which may delay treatment and lead to social isolation, which can hamper recovery. These issues can also reduce employment and education opportunities and result in poorer physical healthcare,

²Mental Health Act Codes of Practice differ in England and Wales. For England, refer to *Code of Practice: Mental Health Act 1983* (Department of Health, 2008a) and for Wales, refer to *Mental Health Act 1983: Code of Practice for Wales* (Welsh Assembly Government, 2008).

suicidality and higher mortality rates (Thorncroft, 2006). Stigma among professionals towards psychosis and schizophrenia may also delay diagnosis and treatment.

Language is one way in which stigma can be influenced for better or worse. Throughout the guideline the term 'psychosis' is used as a shorthand to describe psychotic disorders that are characterised by experiences that are described by clinicians as 'hallucinations' (hearing voices, seeing, feeling or tasting things that others cannot) and 'delusions' (believing in things that are not deemed to be based in reality). It is important to note that many people who hear voices would not define their experiences as either 'hallucinations' or 'psychosis', or indeed as pathological, and many individuals who are viewed as having 'delusions' would not identify their beliefs as such or consider their experiences to be 'psychosis'. Part of the difficulty and confusion around terminology in this area may arise because the term 'psychosis' is sometimes used interchangeably to refer to both psychotic symptoms (which may be common and not impairing) and a psychotic disorder (for example, schizophrenia), which is rare and associated with functional impairment. In this guideline the term 'psychosis' is reserved to refer to psychotic disorder.

The experience of being diagnosed can also be a cause of disempowerment for people with psychosis and schizophrenia and lead to the creation of a new identity as a 'schizophrenic', thus promoting social exclusion (Pitt *et al.*, 2009). Diagnostic labels can be particularly divisive, with terminology such as 'schizophrenic' generally being recognised as unacceptable to people with psychosis and schizophrenia. Personal accounts emphasise that the diagnostic 'label' is difficult to shed and can take on a life of its own, dehumanising and devaluing the individual (Bjorklund, 1996). Therefore, when referring to people with such diagnoses, the guideline employs terminology such as 'people who have psychosis and schizophrenia' rather than 'schizophrenic'. The term 'service user' is used for individuals who use mental health services.

2.7 ISSUES FOR PARENTS AND CARERS

As many children and young people offered treatment for psychosis and schizophrenia will still be in the direct care of parents or carers, it is important to consider developing treatments and decision-making processes that involve parents and carers as much as possible. At the same time, however, young service users will also need opportunities for confidential discussion of their concerns, as some of these may relate directly to difficulties with family members or carers.

While developing the most appropriate and effective intervention strategy for psychosis and schizophrenia with children and young people, it is important to remember that this age group, as well as their parents or carers, may have different priorities and preferences for treatment than older service users (see Section 2.5). This includes addressing the normal developmental tasks of adolescence with young people and their parents and carers as well as managing the psychotic disorder. It is also important to consider carefully the effectiveness and safety of particular treatments that have been developed for adults when recommending similar treatments for children and young people, and to offer service users and their parents or carers full

information about the relative costs and benefits of any recommended treatments (for example, long-term side effects of antipsychotics versus potential short-term reduction in psychological distress).

2.8 TREATMENT AND MANAGEMENT OF PSYCHOSIS AND SCHIZOPHRENIA IN CHILDREN AND YOUNG PEOPLE IN THE NHS

2.8.1 Pharmacological interventions

Medication has formed the mainstay of treatment for psychosis since the introduction of chlorpromazine in the 1950s. Today, antipsychotic medication is considered an important part of a comprehensive package, which should also include psychological treatments and psychoeducation for the service user and their family. Antipsychotics are being prescribed more widely, and in one national survey (Nielsen *et al.*, 2010) this was associated with less inpatient use for those with first episode psychosis.

There has been a substantial increase in the prescription of antipsychotic medications for children and young people (Vitiello *et al.*, 2009) with evidence also of a change of use from so-called ‘first generation’ antipsychotics (FGAs) such as haloperidol to ‘second generation’ antipsychotics (SGAs) such as olanzapine and risperidone. The latter drugs were introduced and marketed as being more effective and less likely to cause side effects, particularly extrapyramidal movement disorders and parkinsonism. However, recent evidence in this age group indicates there are few advantages of SGAs over FGAs in treating psychosis (Armenteros & Davies, 2006; Kennedy *et al.*, 2007, updated 2012; Sikich *et al.*, 2008). Indeed, weight gain, risk of diabetes, and metabolic problems associated with SGAs raise important public health concerns given the widespread use of these medications (Sikich *et al.*, 2008). Dietary and lifestyle counselling are required when initiating antipsychotic treatment alongside continued monitoring for adverse effects to optimise physical as well as psychiatric outcomes (Correll, 2011). Caution is further heightened by the finding that, generally, side effects in children and young people appear more severe than in adults (Correll, 2011). The lower rate of tardive dyskinesia with SGAs (Correll & Schenk, 2008) is potentially an argument in favour of SGAs over FGAs. With the notable exception of clozapine (Gogtay & Rapoport, 2008), there is no evidence for greater efficacy of one antipsychotic over another in the treatment of psychosis in this age group; choice may, therefore, be guided by the side-effect profile (Correll, 2010). Switching of antipsychotics ideally requires knowledge of the drug safety, efficacy, receptor profile and use of a tapering schedule (Buckley & Correll, 2008).

There is increasing evidence from meta-analyses of RCTs (Armenteros & Davies, 2006; Kennedy *et al.*, 2007, updated 2012) confirming the efficacy of antipsychotic medication in children and young people. Antipsychotic medication is effective in reducing the positive symptoms of psychosis (hallucinations, delusions and thought disorder), however, the effect size is modest (0.2 to 0.3) according to Cohen’s (1992) criteria. Furthermore, there is limited evidence to suggest efficacy of these medications

against negative symptoms of psychosis (lack of motivation, poverty of thought and so on). The relative lack of efficacy is a concern because early-onset schizophrenia is noted to be more severe, with greater cognitive impairment, increased negative symptoms, and less response overall to treatment than adult-onset schizophrenia (Correll, 2010; Eggers & Bunk, 2009).

Although there is some commonality in the pharmacotherapy of psychosis in adults and younger people, some important differences exist. Children and young people are more sensitive to the effects of medication (Correll, 2011) and therefore what is done during initiation of treatment is particularly important, such as starting with a low dose, whenever possible, and gradually titrating upwards over a period of several days to weeks. Although drug metabolism may be more rapid in young people than in adults (suggesting the possible need for higher doses) the use of higher than *British National Formulary*³ (BNF) doses of antipsychotics does not appear effective—with only indirect evidence for high-dose olanzapine (Kumra *et al.*, 2008b)—and is not recommended unless guided by drug levels (for example, when treating with clozapine). It is also worth noting that for the most part the use of antipsychotic medication in children and young people is off-licence, therefore when prescribing off-label it is important to make parents and carers and, where appropriate, children and young people aware of this.

Psychoeducation for the child/young person and their family/carers is important, particularly as long-term compliance with medication is generally poor, and likely to be one of the major reasons for relapse. Unfortunately, strategies to enhance compliance have not been shown to be generally effective (Lincoln *et al.*, 2007), although the evidence is limited. Nevertheless, explanation, guidance and involving the family or carers in decisions about medication are important, as is continuity of care, especially across the transition of adolescence to early adulthood.

2.8.2 Psychological and psychosocial interventions

Before the introduction of neuroleptic medication for schizophrenia in the 1950s and 1960s, analytical psychotherapies based on the work of Frieda Fromm-Reichmann (1950) and Harry Stack Sullivan (1947) and others were widely practiced. The concept of rehabilitation grew during this period influenced by the pioneering work of Manfred Bleuler in the Bergholzi clinic in Zurich where patients were engaged in meaningful vocational and occupational endeavour in the context of an ‘open door’ policy (Bleuler, 1978). In the early 1980s, the publication of the seminal ‘Chestnut Lodge’ evaluation of exploratory and investigative psychotherapies (McGlashan, 1984) had a major impact: the trial demonstrated no impact of psychotherapy on the core psychotic symptoms contributing to a decline in their use in routine practice with the neuroleptics taking their place as the mainstay of treatment.

³<http://www.bnf.org/bnf/index.htm>

However, as deinstitutionalisation gained ground in the 1970s, psychological and social research into factors that might contribute to relapse in people with psychosis living in community settings, such as stressful life events and communication difficulties in families (high 'expressed emotion'), stimulated the development of family intervention to prevent relapse (Leff *et al.*, 1982; Lobban & Barrowclough, 2009). Family intervention often included education for family members about schizophrenia (sometimes called 'psychoeducation') and, in time, research was conducted on the benefits of psychoeducation alone (Birchwood *et al.*, 1992).

Meanwhile, the success of CBT in treating affective disorders sparked a renewed interest in 'talking therapies' for psychosis. One of the key progenitor studies was the work of Chadwick and Lowe (1994) showing that it was possible to 'reason' with people about their delusions and to reduce the strength of delusional beliefs. This was followed by the work of a number of groups in the UK developing cognitive models of psychosis (Garety *et al.*, 2001; Morrison *et al.*, 2004b) and of specific symptoms such as hallucinations (Chadwick & Birchwood, 1994) and applying the assumptions and techniques of CBT to psychosis (for example, Kingdon & Turkington, 1994; Fowler *et al.*, 1995). CBT is a very complex intervention in psychosis, working not only with delusions and hallucinations, but including a broad focus on self-evaluative thinking, which can require up to 25 sessions of treatment. There has been much debate about the future development of the CBT approach including the view (Birchwood & Trower, 2006; Fowler *et al.*, 2011) that it needs to focus on the interaction of affect and psychosis and on the high level of affective disturbance seen in psychosis (depression and suicidal thinking, social anxiety and trauma symptoms). CBT has been developed further to reduce the likelihood of relapse, including young people with a first episode of psychosis (Álvarez-Jiménez *et al.*, 2011).

Another approach, cognitive remediation therapy (CRT), was also developed in the 1980s and 1990s, and differs from CBT in that it is not directed at distressing symptoms but is instead focused on training in cognitive functions, such as learning, planning, attention or memory (Wykes *et al.*, 2011); these have been linked with negative symptoms and general functioning. CRT is, however, rarely available in the NHS. In the mid 1990s a specific cognitive behavioural approach that aims to enhance compliance with medication, now commonly known as 'adherence therapy', was also developed (Kemp *et al.*, 1996). Arts therapies that emerged as organised professions in the middle of the last century have in recent years begun to be evaluated formally in trials (Crawford & Patterson, 2007). Finally, there has been a focus on structured approaches to access employment for people with psychosis, particularly 'individual placement and support', which has great relevance for young people with psychosis (Killackey *et al.*, 2008).

2.8.3 Factors influencing treatment approaches

Since the 1980s there has been an emerging consensus that schizophrenia in children and young people represents essentially the same disorder as seen in adults. Despite a much more limited evidence-base there is also consensus that psychosis

and schizophrenia in children and young people should generally be treated with the same interventions that are effective in adults. However, there are also a number of important differences between children/young people and adults that influence treatment approaches. These include:

- increased sensitivity of children and young people to adverse effects of antipsychotic medication
- greater severity of schizophrenia and prevalence of treatment resistance in children and young people
- a different pattern of comorbidities, with neurodevelopmental disorders (for example, autism, receptive language disorders and so on) being more common in children and young people with psychosis and schizophrenia
- a greater likelihood of cognitive impairment, negative symptoms and less systematised delusions and hallucinations (possibly limiting the universal applicability of cognitive behavioural therapy [CBT] approaches) in children and young people
- the importance of families in providing care and supporting children and young people with psychosis and schizophrenia (emphasising the importance of family intervention).

2.8.4 Management of at risk mental states and early psychotic symptoms

Reliable and valid criteria are now available to identify help-seeking individuals in diverse settings who are at high risk of imminently developing schizophrenia and related psychoses (see Section 2.1.2). Yung and colleagues (1996) developed operational criteria to identify three subgroups possessing an at risk mental state for psychosis. Two subgroups specify state risk factors, defined by the presence of either transient psychotic symptoms, also called brief limited intermittent psychotic symptoms, or attenuated (subclinical) psychotic symptoms. The other subgroup comprises trait-plus-state risk factors, operationally defined by the presence of diminished functioning plus either a first-degree relative with a history of psychosis or a pre-existing schizotypal personality disorder. All subgroups are within a specified age range known to be at greatest risk for the onset of psychosis.

Effective interventions to prevent or delay transition to psychosis are needed because of the significant personal, social and financial costs associated with it. To date there have been six randomised controlled trials (RCTs) that have reported outcomes associated with antipsychotic medication, omega-3 polyunsaturated fatty acids and/or psychological interventions, each using similar operational definitions of at risk mental states. These studies have been conducted in Australia (McGorry *et al.*, 2002; Yung *et al.*, 2011), North America (Addington *et al.*, 2011; McGlashan *et al.*, 2006), the UK (Morrison *et al.*, 2004a and 2007) and Austria (Amminger *et al.*, 2010).

It is generally agreed that research regarding interventions for at risk mental states and subthreshold psychotic experiences is in a state of clinical equipoise. Existing recommendations promote a clinical staging approach that utilises benign interventions (such as monitoring mental states, case management, social support and psychosocial interventions) before considering those with more significant side effects,

such as antipsychotic medication, or restrictive approaches involving hospitalisation (International Early Psychosis Association Writing Group, 2005; McGorry *et al.*, 2006). However, due to local resources and service configurations, clinicians' attitudes and awareness of such recommendations, current clinical practice is likely to be highly variable, which is evident in the recent large international naturalistic cohort studies (Cannon *et al.*, 2008; Ruhrmann *et al.*, 2010).

2.8.5 Organisation of care

Child and adolescent mental health services (CAMHS) and early intervention in psychosis (EIP) services

Until the 1990s most children and young people with psychosis and schizophrenia were managed in child and adolescent inpatient units. The last decade of the 20th century saw a major change in service delivery with a shift towards community treatment in CAMHS. The first decade of this century saw the development of EIP services, with a policy implementation guide (Department of Health, 2001) recommending that these services should be provided for young people aged 14 to 35. EIP teams are generally managed by adult mental health services (AMHS) although some are embedded within CAMHS.

In 2004 CAMHS were directed by the *National Service Framework for Children, Young People and Maternity Services* (Department of Health, 2004)⁴ to provide care for young people up until the age of 18. Prior to this the upper age range for CAMHS could vary according to whether the young person was in receipt of full-time educational provision. A recent report on this subject (Rethink, 2011) illustrates that this continues to be the case despite some models of good practice and recommends an agreed protocol for managing young people with psychosis who are under the age of 18, which should be embedded within everyday practice and based on cross-agency agreement of threshold criteria. Given that the policy implementation guidelines for EIP services in 2001 followed on from the *National Service Framework for Mental Health* in 1999 (Department of Health, 1999), it is strange that these recommendations⁵ are still required some 10 years later.

Also in 2004 a group of international experts published a paper with recommendations on the involvement of CAMHS in EIP services (Marshall *et al.*, 2004). There was a strong consensus that EIP services should have close links with CAMHS and be supported to prescribe medication to those aged under 16. There was also consensus that EIP services should integrate CAMHS and AMHS, have at least one representative from CAMHS, have designated sessions from child and adolescent psychiatry and employ youth workers. Despite this an audit of EIP services in England in 2005

⁴This refers to the National Service Framework for England. For Wales, refer to the *National Service Framework for Children, Young People and Maternity Services in Wales* (Welsh Assembly Government, 2004a).

⁵In the original policy implementation guideline (HMSO, 2001) there was a recommendation of 0.1 whole time equivalent child and adolescent psychiatrist as part of the EIP service.

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(Pinfold *et al.*, 2007) found that only 16% of EIP teams had dedicated input from CAMHS or youth workers. A quarter of EIP teams did not see young people under the age of 16.

The Rethink (2011) report found that of staff working in EIP/AMHS, 91% had not received training to work with those aged under 14 years; 67% reported that their staff had not received training to work with 14 to 16 year olds; and 64% reported that their staff had not received training to work with 16 to 18 year olds. Over 50% of EIP teams responded that they were not identifying young people in CAMHS with first episode psychosis or at risk of developing psychosis. One of the most commonly reported explanations was interface problems and role confusion between EIP and CAMHS teams.

In 2006 the Newcastle and North Tyneside EIP team sought to address this issue by appointing a consultant child and adolescent psychiatrist as an integral EIP team member rather than referring to, potentially, eight different CAMHS and consultant psychiatrists. In 2006 this was cited as a model of good practice in a review of the implementation of Part 9 of the *National Service Framework for Children, Young People and Maternity Services* (Department of Health, 2006a) and has been presented as a case study in the Rethink (2011) report. This is not to say that this is the preferred model for integrating EIP and CAMHS. What is likely to be the predominant model nationally is for young people with psychotic symptoms to be referred to CAMHS or EIP services but possibly receiving care that comprises components of both. For example, young people may be most likely to receive care coordination from EIP services but psychiatric input from CAMHS.

Admission to hospital

A child or young person experiencing psychosis or schizophrenia may be admitted to a range of inpatient settings. In part this will depend upon clinical features, for example, age (child or adolescent), the nature or purpose of admission (planned, crisis or emergency), level of disturbance and risk, and intensity of nursing care required. But in part it will also be determined by local service configuration and provision. The 2007 amendments to the *Mental Health Act* (HMSO, 2007) have made it much less likely that a child or young person will be admitted to an adult mental health ward unless this is clearly appropriate to their very specific needs.

CAMHS inpatient units are characterised by their emphasis on meeting the developmental needs of the individual and minimising the impact of the disorder and the admission on the child or young person's emotional, social and educational development. Such units are likely to have a strong multidisciplinary team including an integrated education provision. The Quality Network for Inpatient CAMHS (QNIC) aims to demonstrate and improve the quality of inpatient child and adolescent psychiatric inpatient care through a system of review against the QNIC service standards (Royal College of Psychiatrists, 2011).

However, demand for age appropriate mental health beds frequently outstrips supply and alternative solutions may be necessary, particularly in a crisis. This can include brief mental health supported admission to a paediatric environment. It should be borne in mind that the range of provision that exists in AMHS for managing acute

presentations in or out of hospital (for example, crisis resolution and home treatment, acute admission and psychiatric intensive care) is less well developed in CAMHS and partnership with, or provision from, other non-NHS providers may be necessary.

Admission to hospital is disruptive to all aspects of a child or young person's life and the gains of admission do need to outweigh the losses. However the experience of psychosis is also extremely disruptive and may require the specialist skills or resources in assessment, risk management or treatment that can only be provided by admission. Admission to hospital should always be seen as one part of a child or young person's pathway through services and never as an end itself. There should be close liaison and collaboration between community services and any inpatient unit throughout the period of admission. The care programme approach (CPA) (Department of Health, 2008b) and care and treatment plans (C&TP)⁶ provide the appropriate frameworks within which this should take place.

2.8.6 Pre-pubertal children

Treatment for pre-pubertal children is generally offered within the framework of the consent of those with parental responsibility for the child. However it is good practice to involve and inform the child in a manner that is appropriate to their developmental level and this requires clinicians to be confident in the assessment of the child's level of understanding and competence. Information leaflets using simple language may be helpful. Children may need several discussions and opportunities to ask questions about their condition and the treatments that they are being offered. Parents and carers should be expected to be actively involved in the treatment, which may include family intervention, psychoeducation and CBT targeted at symptoms, as well as pharmacotherapy (Hollis, 2008; Kennedy *et al.*, 2007).

There is some evidence that childhood-onset schizophrenia improves with antipsychotic medication (Kennedy *et al.*, 2009; James, 2010). Children may be more sensitive to the side effects of antipsychotic medication (Correll, 2008; James, 2010; Kumra *et al.*, 1996), therefore physical healthcare, baseline investigations and ongoing monitoring of side effects of drug treatment need to form part of the treatment package (see Chapter 7). For children who have not responded to other medications, clozapine appears to have some benefits in the treatment of psychotic symptoms and improving general functioning (James, 2010; Kennedy *et al.*, 2009; Kumra *et al.*, 1996). Given that many antipsychotic drugs are not licensed for use in younger age groups, children are often treated using licensed medication for an unlicensed indication. It is good practice to inform parents and carers of this fact and give them an opportunity to ask questions.

Children may come to the attention of either paediatric services or community CAMHS, which generally provides the initial treatment package. Inpatient care may

⁶Mental Health (Wales) Measure 2010. See: <http://www.assemblywales.org/bus-home/bus-legislation/bus-leg-measures/business-legislation-measures-mhs-2.htm>

become necessary for clarification of diagnosis, detailed assessment or risk management—this would usually be provided in a Tier 4 CAMHS specialist inpatient unit. In the absence of suitable CAMHS inpatient provision, children may be admitted to a paediatric ward. Strong links between community CAMHS and the inpatient paediatric service need to be maintained during treatment. Protocols across services may help to clarify lines of responsibility. Occasionally treatment may be required under the *Mental Health Act 2007* (HMSO, 2007).

2.8.7 Primary–secondary care interface

Pathways to specialist care can be particularly problematic for people with psychosis and schizophrenia under the age of 18. A study of first time presentations in young people in central Scotland (study population 1.75 million) reported that 80% were hospitalised, often onto adult wards, suggesting most had reached crisis before engaging specialist services (Boeing *et al.*, 2007). Crisis response also featured in a first episode psychosis study in London and Nottingham where 40% of those presenting to generic community services required compulsory admission, rising to 50% for young black men (Morgan *et al.*, 2005). This study linked general practitioner (GP) involvement with fewer legal detentions reported previously (Cole *et al.*, 1995; Burnett *et al.*, 1999), suggesting that it decreases the likelihood of police involvement and compulsory admissions. Moreover, GPs are frequently consulted in a first episode and are the most common final referring agency (Cole *et al.*, 1995; Skeate *et al.*, 2002).

Although GP participation in the pathway can reduce distress and delay in treatment, GPs may hold negative opinions about providing care for people with psychosis and schizophrenia (Lawrie *et al.*, 1998) believing that the prevalence is too low to justify more active involvement (Bindman *et al.*, 1997). Rarity of presentation was highlighted by a Swiss study, which found that GPs suspect an emerging psychosis in only 1.4 service users a year (Simon *et al.*, 2005) and the proportion under 18 would be fewer still as 20% of people with a first episode are under 20 and 5% are under 16 (Hollis, 2003). Moreover early features may be difficult to distinguish from normal adolescent behaviour and substance misuse (Etheridge *et al.*, 2004; Falloon, 2000). Few GPs receive postgraduate mental health training, but evidence of the effects of training is mixed. A study of a GP educational intervention about early presentations of psychosis failed to reduce treatment delay, although the training may have facilitated access to EIP teams (Lester *et al.*, 2009). Indeed when asked, GPs prefer better collaboration with specialist services and low-threshold referral services rather than educational programmes (Simon *et al.*, 2005).

The other major interface difficulty concerns the management of associated physical disorders due to poor organisation of health services and an ongoing failure by medical doctors in primary and specialist care to agree responsibility (Leucht *et al.*, 2007; *The Lancet*, 2011). Despite numerous published screening recommendations, monitoring rates remain poor in adults (Mackin *et al.*, 2007; Buckley *et al.*, 2005; Morrato *et al.*, 2009; Nasrallah *et al.*, 2006) and children (Morrato *et al.*, 2010). European screening and monitoring guidelines for diabetes and cardiovascular risk in

schizophrenia offered no specific guidance on the risks in children and young people (De Hert *et al.*, 2009). A recent systematic review concluded that good collaboration among child and adolescent psychiatrists, GPs and paediatricians is essential for the monitoring and management of severe adverse effects of antipsychotics (De Hert *et al.*, 2011).

GPs are more likely to accept physical healthcare as a core role (Lester *et al.*, 2005). The Quality and Outcomes Framework (QOF) (BMA & NHS Employers, 2011) has incentivised GPs to undertake annual physical health checks in people with psychosis and schizophrenia since 2004, reinforced by the NICE *Schizophrenia* guideline for adults (NICE, 2009a) which allocates overall responsibility to primary care for managing physical healthcare. However, the QOF and the NICE guideline do not prioritise the physical needs of young people with early psychosis. What is perhaps lacking is recognition of a group of many thousands of young people in adolescence and early adulthood, at ages primary care would not normally consider for active cardiovascular prevention, who are at high risk of dying prematurely. Whether from primary or specialist clinicians, these young people require clear and consistent information, particularly about the benefits and risks of antipsychotic medication to help them and their families or carers understand and balance improved mental health symptoms against increased risks to physical health.

Given that ‘modifiable cardiovascular risk’ appears within months of starting treatment with antipsychotics (Foley & Morley, 2011) the onus should arguably shift towards prevention and early intervention by those specialist services responsible for the critical early phase (Phutane *et al.*, 2011). However, simply issuing more guidance, for instance, to EIP services, is unlikely to change clinical practice without investing in systematic approaches to analysing and understanding the barriers to routine monitoring, organisational commitment to overcoming these, and clinical leadership (Hetrick *et al.*, 2010).

2.9 SUPPORTING CHILDREN AND YOUNG PEOPLE WITH PSYCHOSIS AND SCHIZOPHRENIA IN SCHOOL

2.9.1 Recognising psychosis and schizophrenia in schools

It is estimated that up to three out of 1000 secondary school pupils might be expected to be at risk of developing psychosis. Staff in secondary schools should be aware that some of their pupils are likely to develop early-onset psychosis and schizophrenia particularly around times of stress such as examinations. There are a number of signs that can indicate that a young person is becoming unwell and possibly developing psychosis. These prodromal symptoms may include social withdrawal, increasingly bizarre ideas and perceptual experiences, deteriorating concentration and academic performance (see Section 2.1.1). Those staff with a greater knowledge of individual pupils, such as form tutors, year heads or others with pastoral responsibilities, need to be alert to persistent changes in mood or demeanour (lasting for more than 3 weeks).

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If these changes are persistent, school staff may consult with pupils, parents and carers and share their concerns. As a consequence, it may be necessary to discuss the matter further with other professionals working in schools (such as educational psychologists, school doctors or school nurses) who may well carry out further structured observations. If there is no improvement, they may well ask if the pupil and their parents or carers would accept referral to CAMHS or an EIP team.

2.9.2 Supporting children and young person in school

Children and young people will often feel distressed and frightened by their psychotic symptoms. They will be aware that other people do not experience the world in the same way that they do. This is disturbing in itself, however the experiences of a young person with psychosis can be worsened by the responses of those around them. If, for example, the young person is mocked or bullied for their different view of reality, this will exacerbate their fear and isolation. All schools now have anti-bullying policies and it is essential that they are operational and function effectively in order to best support all young people including those with psychosis and schizophrenia.

If school staff are inexperienced or concerned about supporting a child or a young person with psychosis or schizophrenia they have a responsibility to seek support themselves through a supervisory process perhaps from the school educational psychologist or other mental health workers.

As the condition progresses it may become increasingly difficult for the child or young person to continue in full-time education. They may be unable to sustain long periods of academic work and cope with the many interactions that comprise a school day. In these circumstances alternatives to full-time education may need to be considered. It is beneficial if alternatives can be planned for and discussed by those supporting the child or young person in advance. Breakdown of school placement and consequent emergency admission to some alternate provision will only add to the fear felt by the child or young person.

2.9.3 Returning to full-time education

When the child or young person is recovering, it is appropriate that in time they should be able to return to full-time education. School staff need to prepare for re-admission and be quietly welcoming. Environments with high levels of expressed emotion are known to increase the likelihood of a relapse into psychosis and schizophrenia, and it might be beneficial if pastoral staff who are aware of such environments within the school structure a timetable to avoid or minimise exposure to such classes, in consultation with the child or young person. At the same time it may be appropriate to provide opportunities for quiet and limited social interaction as part of each day. It is important to remember that a young person with psychosis or schizophrenia is experiencing an illness as devastating in its impact as leukaemia and they deserve the same levels of care, respect and support from those in educational settings.

2.10 THE ECONOMIC COST OF PSYCHOSIS AND SCHIZOPHRENIA

In 1990 the World Health Organization ranked schizophrenia as the ninth leading cause of disability. Assessment indicators of disability-adjusted life years (DALYs), such as non-fatal health outcomes as well as the premature mortality ratio for the condition, rank it as the 26th leading cause of global economic burden and the ninth leading cause of DALYs for people aged 15 to 44 years (Murray & Lopez, 1996).

The reported total cost of schizophrenia in the US amounted to US \$62.7 billion in 2002 (Wu *et al.*, 2005). Over 50% of this cost was attributed to productivity losses, caused by unemployment, reduced workplace productivity, premature mortality as a result of suicide and family care. An average of 36% of the cost has been linked to direct healthcare service use, while 12% has been incurred by non-healthcare services. Several national studies conducted in Europe in the 1990s revealed schizophrenia 'was associated with a significant and long-lasting health, social, and financial burden, not only for patients but also for families, other caregivers, and the wider society'. (Knapp *et al.*, 2004).

The cost of treatment of people with schizophrenia is incredibly high, especially for those who require inpatient treatment and other psychiatric care facilities. In England approximately £2 billion of the estimated societal cost for schizophrenia of £6.7 billion (2004–2005 prices; Mangalore & Knapp, 2007) was accounted for by direct costs of treatment and care. The remaining £4.7 billion constituted indirect costs borne by society. Other costs, including the lost cost of productivity owing to unemployment, absence from work and premature mortality have been estimated at £3.4 billion and the cost of carers has been estimated roughly at £32 million. Other unanticipated costs include the cost of informal care and private expenditure borne by families, which has been estimated at roughly £615 million. In addition, the cost attributed to the criminal justice system amounts to nearly £1 million. The costs associated with administration relating to all of the above payments also need to be factored in – so far, these have been calculated at £14 million. Based on these estimates, the annual average cost borne by a person with schizophrenia in England can easily exceed £55,000.

There is a necessary distinction to be made when allocating economic costs to people with schizophrenia. Traditionally, newly diagnosed schizophrenia is of a considerably lower financial burden than chronic schizophrenia. According to Davies and Drummond (1994), the lifetime total direct and indirect financial costs borne by people with schizophrenia who have had a single episode can range from £8,000; for those experiencing multiple episodes, lasting more than 2.5 years, the estimated cost is nearly £535,000, factoring in long-term care in hospitals, private psychiatric facilities and/or intensive community programmes (1990/1991 prices). Guest and Cookson (1999) revised this estimate after taking into account the estimated average costs borne by a newly diagnosed patient at around £115,000 over the first 5 years following diagnosis. This amounts to nearly £23,000 annually, where 49% of the cost is directly attributed to indirect losses owed to lost productivity.

A recent review reported that the rate of unemployment among people with schizophrenia in the UK was between 4 and 27%. Stigmatisation has been cited as a

leading barrier to employment for this population. Unemployment rates were higher for those who were newly diagnosed compared with those living with established schizophrenia, however, a majority of people presenting to services for the first time were already unemployed (Marwaha & Johnson, 2004). According to Guest and Cookson (1999) between 15 and 30% of people with schizophrenia are unable to work at the diagnosis stage and this figure is expected to rise to approximately 67% following a second episode. Overall, the estimates of total indirect costs for patients in the UK range from between £412 million for newly diagnosed patients over the first 5 years to £1.7 billion annually for chronic patients (Davies & Drummond, 1994).

The use of inpatient care is often significant and in the financial year 2006–2007, 34,407 admissions were reported for schizophrenia and related disorders in England. This resulted in 2,232,724 inpatient bed days and amounted to 16% of all admissions and 34% of all bed days for psychiatric inpatient care (NHS, Information Centre, 2008). Inpatient care is by far the most costly healthcare component in treating schizophrenia. Kavanagh and colleagues (1995) found that in short- or long-stay psychiatric hospitals the cost accounted for 51% of the total public expenditure for the condition. Lang and colleagues (1997) reported that providing inpatient care amounted to 59% of the total cost of health and social care for people with schizophrenia.

Perhaps the cost that is most often overlooked and the hardest to allocate is that associated with informal care. Family members and friends often provide care for people with psychosis and schizophrenia, including children, and this places a substantial burden on their health, time, finances and employment status. Guest and Cookson (1999) estimated that at least 1.2 to 2.5% of carers in the UK stop working to look after dependents with schizophrenia. Measuring this cost in exact financial terms is difficult, however, it does form a significant component of the total economic costs associated with the condition. Based on Office for National Statistics (ONS) figures, the Sainsbury Centre for Mental Health (2003) estimated that in 2002/2003 the aggregate value of informal care by family members and friends in the UK for people with mental health problems amounted to £3.9 billion.

It is clear that apart from the emotional and mental strain borne by people with schizophrenia and their family there is a substantial economic burden that individuals, the healthcare system and society need to contend with. Efficient use of available healthcare resources is essential to maximise benefits for this population and could go a long way to reduce the emotional stress and other implications that people with schizophrenia, including children and young people, inevitably face.